Spirituality and adjustment to cancer

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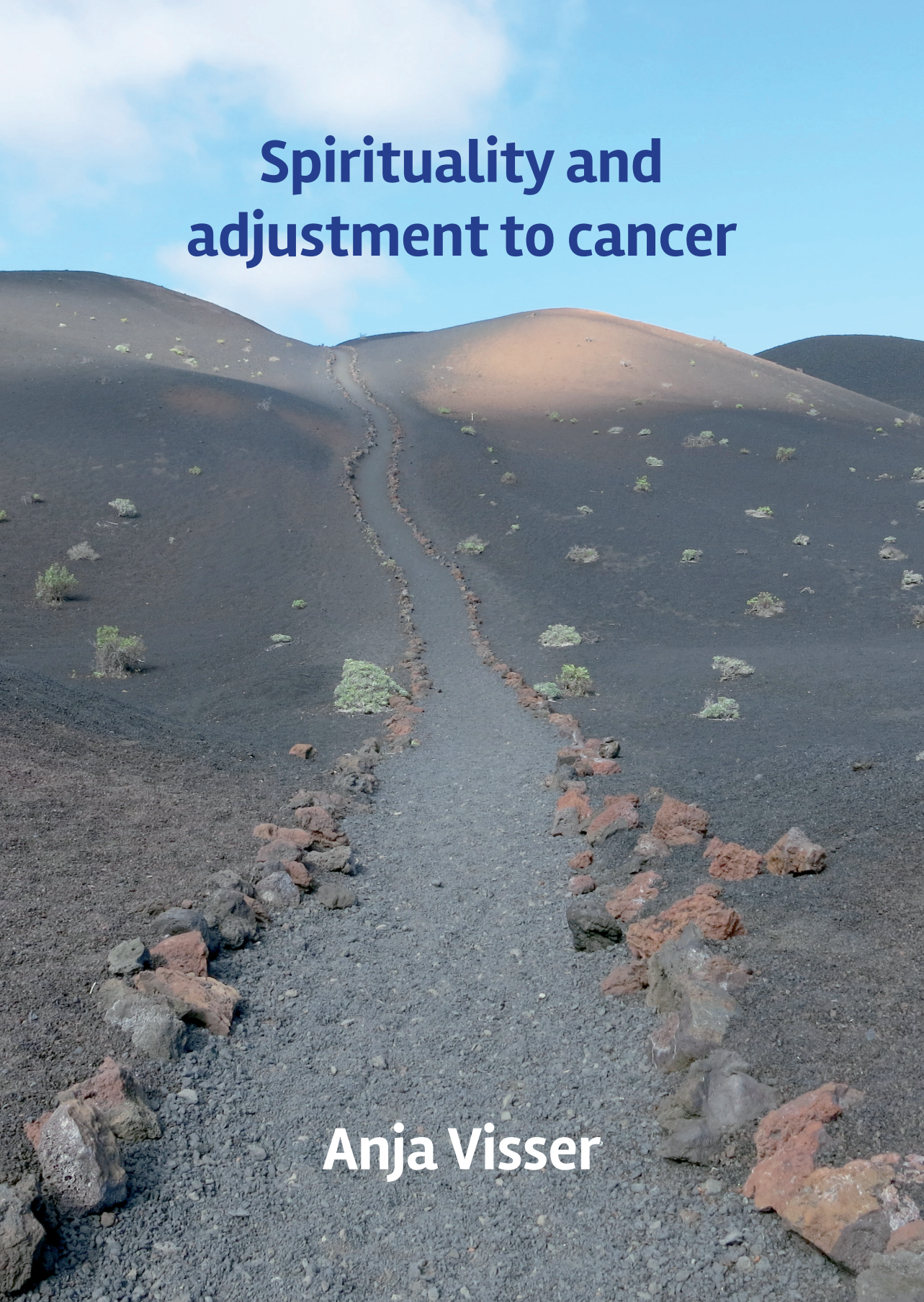

Anja Visser

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Spirituality and adjustment to cancer

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I walked a mile with Pleasure;
She chatted all the way;
But left me none the wiser
For all she had to say.

I walked a mile with Sorrow;
And ne'er a word said she;
But, oh! The things I learned from her,
When Sorrow walked with me.

(Robert Browning Hamilton)

Content

1

Introduction

In this dissertation I investigate the question: What is the role of spirituality in the psychological adjustment to cancer? The diagnosis and treatment of cancer bring about many challenges. For one, the association of cancer with death can bring into awareness that there are boundaries to a person's existence. This can raise existential questions about why this is happening to the person and what he/she finds important in life. Also, even when the cancer can be cured, patients have to learn to cope with uncertainty about cancer recurrence and with physical changes such as scars, pain or fatigue. These changes and uncertainties can put a strain on the person's relationships, self-image, and meaning in life (Fernsler, Klemm, & Miller, 1999; Landmark, Strandmark, & Wahl, 2001; Tulls Halstead & Hull, 2001). Spirituality has been proposed as a source of resilience for people coping with a physical illness. Resilience refers to the ability to maintain or regain mental health in the face of great adversity or risk (Stewart & Yuen, 2011).

In this chapter, I will first discuss what spirituality is. Then I will explore why spirituality might be a source of resilience during the diagnosis and treatment of cancer. Finally, I will give an outline of the chapters that follow.

Spirituality

This dissertation is about spirituality, but what is spirituality? This is a much debated subject within the scientific, philosophical, and theological literature. The debate centers around two questions: What is the relationship between spirituality and religion, and how can we define spirituality to enable research on this subject?

Spirituality versus religion

Let us first consider the relationship between spirituality and religion. We ask ourselves the following questions: Do spirituality and religion encompass each other or are they different constructs? And if they are encompassing, which one is the broader construct?

The debate on the definition of spirituality and its relationship with religion is the result of a societal shift, wherein people are no longer members of a religious institution, but may still define themselves as a spiritual person (Fuller, 2001). In the Netherlands, this process of the 'secularization' is described by de Hart (2011), who found that between 1966 and 2006 the proportion of Dutch people who were a member of a church had declined with 42%, while the proportion of non-members increased with 85%. In the same time period the proportion of theists declined with 49%, whereas the proportion of 'somethingists' increased with 16%, the proportion of agnostics increased with 63%, and the proportion of atheists increased with 133%. The rise in 'somethingist' and agnostics confirms that, even though people move away from the church, they still seem to believe in (or are at least open to the possibility of) a God or some larger power. This shift to 'believing without belonging' (Davie, 1994) is reflected in people's self-identifications as 'spiritual, but not religious' or 'both spiritual and religious'.

Table 1.1 shows the proportions of people that consider themselves either 'only spiritual', 'only religious', 'both spiritual and religious', or 'neither spiritual nor religious' in two American studies (Shahabi et al., 2002; Zinnbauer et al., 1997) and in two European studies (Barker, 2008; Berghuijs, Pieper, & Bakker, 2013a). There are few people who consider themselves to be only religious, but there are (much) more people who consider themselves either only spiritual or both religious and spiritual. Thus, religion and spirituality seem to be independent, but related constructs. Table 1.1 further reveals that in the two studies conducted in the United States of America the proportions of people who self-identify as 'spiritual and religious' is much higher than in the studies conducted in Europe and in the Netherlands, respectively. In contrast, a larger proportion of European and Dutch people consider themselves either 'only religious' or 'neither religious, nor spiritual'. So, there also seem to be cultural differences in the relationship between spirituality and religion.

Table 1.1 Percentages of people self–identifying as religious and/or spiritual

	Zinnbauer et al. (1997)	Shahabi et al. (2002)	Barker (2008)	Berghuijs et al. (2013a)
Region	USA	USA	Europe	Netherlands
(sample size)	(N = 346)	(N = 1422)	(N = 7378)	(N = 2334)
Group				
Only spiritual	19	10	12	19
Only religious	4	9	15	16
Spiritual and religious	74	52	37	25
Neither spiritual nor religious	3	29	35	40

Heelas and Woodhead (2005) describe the shift from religion to spirituality as a spiritual revolution, in which 'life-as religion' - with roles, duties, and obligations that are dictated by the dogma of a religious institution - makes way for 'subjective-life spirituality' - in which we live our lives in deep connection with our unique selves in relation to the 'other'. Waaijman (Waaijman & Carm, 2003; Waaijman, 2006) describes this process in the context of Christianity. He indicates that in earlier times 'primordial spirituality' was dominant. This type of spirituality centers around the personal experience of the transcendent within the family unit. With the rise of city culture and industrialization, primordial spirituality gave way to schools of spirituality, which developed value- or meaning systems to guide the spiritual journey of their pupils. However, as societies and the schools of spirituality (or 'religions') became larger, they also became more formalized, which put the experiences and development of the individual under increasing pressure. After World War II, and especially since the 1960s,

the focus of Western cultures returned to the individual experience, and primordial forms of spirituality began to regain their popularity. It seems to be this counter movement that has created the differentiation between religion and spirituality; with religion referring to an organized system of beliefs, practices, rituals, and symbols, and spirituality referring to a personal quest for understanding answers to ultimate questions about life, meaning, and relationships (McCullough, Larson, & Koenig, 2001). This historical view, thus, also suggests that spirituality and religion are related, but independent. Religion and spirituality seem to consist of two different approaches to the self. On the one hand, the self is subject to a predetermined meaning system or worldview, while, on the other hand, the self is the object which develops its own meaning system. But how different are these two meaning systems? De Hart (2011) indicates that, despite having left the church, many people retain elements of their (Christian) faith tradition, such as a belief in God, life after death, and the usefulness of prayer. However, the meaning of these beliefs changes. For example, de Hart found that of the 40% of Dutch people who believe in life after death, 13% interpret this as remaining in the memories of others and 21% interprets it in terms of reincarnation. In addition, some elements of the faith tradition are sworn off when people leave the church, such as the belief that the Bible is the word of God or that Christ is the son of God. So, there seems to be a difference in the meaning systems of religious and spiritual people.

Several studies have investigated such differences in more detail (see Table 1.2). The findings from these studies confirm the distinction between religiosity as endorsing values, beliefs, and activities that are associated with tradition and particular institutions, and spirituality as endorsing values, beliefs, and activities that are not confined to a particular institution and are subject to change. Interestingly, Berghuijs and colleagues (2013a) found that among the people who self-identified as ‘spiritual and religious’ one cluster of people identified more strongly with traditionally religious aspects (prayer, affiliation, and religious service attendance), whereas another cluster of people identified more strongly with spiritual aspects.

In short, from this discussion we can conclude that spirituality and religion represent related but different meaning systems. So let us now take a closer look at how spirituality is defined.

Table 1.2 Characteristics of spiritual and religious people

Saucier & Skrzypinska (2008)		Saroglou & Muñoz-García (2008)			Berghuijs et al. (2013a)		
Subjective spirituality	Tradition-oriented Religiousness	Spiritual	Traditionally religious	Emotionally religious	Only spiritual self-identification	Only religious self-identification	Both religious and spiritual self-identification
Tendency toward: – Absorption – Fantasy-proneness – Dissociation – Magical/ superstitious beliefs – Eccentricity High openness to experience	Value: – Authoritarian-ism – Traditionalism – Collectivism Low openness to experience	High value: – Benevolence Low value: – Power – Achievement	High value: – Benevolence – Tradition – Conformity Low value: – Power – Hedonism – Self-direction – universalism	High value: – Benevolence – Conformity Low value: – Power – Hedonism – Self-direction – Universalism – Achievement	– Belief in karma and paranormal issues – Value spiritual transformation – Belief in non-personal higher power	– Religious affiliation – Religious transcendent experiences – Regular prayer – Regular church attendance – Orthodox Christian beliefs – No doubt that God exists	– Religious/ spiritual affiliation – Religious transcendent experiences – Regular prayer – Orthodox Christian beliefs – No doubt that God exists – Value spiritual transformation /personal development – Belief in monism

Note. Subjective spirituality: self-identifying as spiritual, and scoring high on the subscale Spiritual Experiences of the ESI and on the factor Alpha of the SDI. Tradition-oriented Religiousness: self-identifying as religious, and scoring high on the subscale Religiousness of the Expressions of Spirituality Inventory (ESI; MacDonald, 1997) and on the Delta factor on the Survey of Dictionary-Based Isms (SDI; Saucier, 2004). Spiritual: placing high importance on spirituality in life. Traditionally religious: placing high importance on God and religion in life, and frequently engaging in prayer. Emotionally religious: having high interest in the emotion-relational and community aspects, meaning values, and personal experience of religion.

Defining spirituality

Unfortunately, as is the case with many other psychological concepts, it has proven to be difficult to define spirituality; partly because of the debate about the relationship between spirituality and religion, and partly because it is hard to determine where spirituality ends and other psychological concepts begin. To get a grasp on this discussion, I will first describe how spirituality is defined in common parlance and then I will move to scholarly definitions of spirituality. I will conclude with the definition of spirituality that is used in this dissertation.

The people's definition

One way to determine what spirituality is, is to ask regular people what they associate with the word 'spirituality'. When asked to select words from a list that they felt represented spirituality, 254 students and 145 church connected staff in Denmark most often selected: To be connected with something 'of the spirit' (the Danish word is 'åndeligt', which cannot be translated to English according to the authors, in Dutch it would translate to 'geestelijk'), Spirituality (in Danish 'åndelighed' or in Dutch 'geestelijkheid'), Something larger than one's self, Meditation, Religious and supernatural interest, The annual Danish holistic fair 'Body, Mind, Spirit', More between heaven and earth, and Personal relationship to God. They least often selected: Material good, Superficial person, and Money (Hvidt, Ausker, & la Cour, 2012). Berghuijs, Pieper, and Bakker (2013b) found that 2313 Dutch people generally defined spirituality as a belief in a transcendent reality (for example, the existence of higher power, more between heaven and earth, the supernatural, the afterlife; 18%), followed by a belief in the human mind (for example, reflection, a way of thinking, consciousness; 14%), a belief in the non-material (for example, the non-perceptible, intangible, inexplicable; 12%), religion (for example, faith/belief, religion; 12%), and centripetal connectedness (for example, contact with yourself, your innermost, loving yourself; 10%).

Several studies demonstrated that lay definitions of spirituality can be grouped into themes (see Table 1.3). Some people will endorse several of these themes when speaking about their own spirituality, while others might associate spirituality with just one of the themes. Spirituality is often associated with religious beliefs and practices, which indicates that spirituality may be a broader construct than religion and that – despite my earlier conclusion that religion and spirituality are distinct – it may encompass some aspects of religion. However, spirituality is also often related to beliefs and experiences that lie beyond religion, such as paranormal beliefs and a sense of connectedness with other people and nature. In addition, spirituality seems to be associated with aspects of personal life, such as a sense of connectedness with oneself or self-knowledge, mental health, meaning and purpose in life, and everyday activities. This overlap between spirituality and other psychological concepts has caused much trouble for scholars, including me, who are interested in the contribution of spirituality to mental health. We will look at this problem in more detail in Part 1 of this dissertation.

Table 1.3 Definitions of spirituality within common parlance

Hvidt et al. (2012)	Berghuijs et al. (2013b)	Gall, Malette, & Guirguis-Younger (2011)	Mattis (2000)	Zinnbauer et al. (1997)
Danish students and church connected staff	Dutch population sample	Majority Canadian and American population samples	African American women	White American population sample
A positive dimension of human life and mental health (e.g., gratitude, love, meaning in life)	A Christian way of life	Connectedness to the core self (i.e., a belief in a soul or inner essence and a process of reflection that led to self-awareness and conscious living)	Connection to or belief in a higher external power	A feeling or experience of connectedness with God, Christ, a Higher power, a transcendent reality, Nature
A New Age ideology (e.g., healing, crystals, clairvoyance)	Responsibility towards others and nature	A life perspective that provides a framework for understanding life and a guideline for one's actions	Consciousness of metaphysicality (i.e., the existence of souls and spirits and a belief in paranormal phenomena)	Personal beliefs (e.g., in God, a Higher power, the divine, personal values)
An integrated part of established religious life and religious traditions (e.g., God, the names of the major religious traditions, prayer)	Striving for mental health	A relationship with God or a higher power, that is not necessarily personal or connected to a religion	Understanding, accepting, and being in touch with oneself	

(Table 1.3 continued)

A vague striving, opposed to religion (e.g., more between heaven and earth, something larger than oneself, a seeking person)	A life attitude of inwardness	A connection with mystery (i.e., a connection to a force, energy or essence that is intangible and unknown, and an attitude of openness to the supernatural)	Life directions, life instructions, guidance
Selfishness (e.g., anti-intellectual, unappealing, superficial)	The paranormal	A connection to the world, (i.e., others, nature, and deity) that provides meaning and purpose to life	
Ordinary, secular inspiration in human activities (e.g., sports, general and medical science, diet)	Experiencing the transcendent and the non-perceptible	Religion	
	Experiencing the immanent God	Meaningless	
	The transcendent God		

The scholar's definition

We have seen above that the general public does not seem to view spirituality as a coherent, universal phenomenon. However, in order to be able to investigate the effects of spirituality within large populations, such as 'people with cancer', scholars have tried to develop a single definition of spirituality. This has not been an easy feat. Unruh, Versnel, and Kerr (2002) identified no less than 92 different scholarly definitions of spirituality in their literature review. In line with the lay definitions of spirituality, these definitions ranged from the more religious "a relationship to God, spiritual being, higher power" to the more existential "meaning and purpose in life".

Nevertheless, even within this wide range of definitions we find commonalities. Dyson, Cobb, and Forman (1997) indicate that most authors describe spirituality in terms of experiencing a relationship (or connectedness) between self, others, and 'God', being on a quest to find a meaning in life, experiencing hope, having religious or non-religious beliefs that help to explain the meaning of life, and expressing these experiences and beliefs in religious or non-religious practices. Tanyi (2002) seems to arrive at the same conclusion as Dyson and colleagues when, after reviewing 76 articles and 19 books, she defines spirituality as:

> (…) a personal search for meaning and purpose in life, which may or may not be related to religion. It entails connection to self-chosen and/or religious beliefs, values, and practices that give meaning to life, thereby inspiring and motivating individuals to achieve their optimal being. This connection brings faith, hope, peace, and empowerment. (p. 506)

Recently, the North American 'National Consensus Project for Quality Palliative Care' (Puchalski et al., 2009) and the European Association on Palliative Care (EAPC; Nolan, Saltmarsh, & Leget, 2011) have attempted to develop a consensus definition of spirituality with physicians, nurses, psychologists, social workers, pastoral care providers, and health care administrators. The definition by the EAPC builds upon the American definition, so here I cite the definition by the EAPC:

> [Spirituality is] the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seek meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred. (Nolan et al., 2011, p. 88)

These scholarly definitions overlap with the definitions within common parlance and they also clearly present spirituality as the broader construct that can encompass religion. However, we encounter the same problem here as we identified in the lay definitions: These definitions do not seem to provide clear guidelines on the boundaries of spirituality. What does it mean to experience connectedness to self, others, and nature in a spiritual way? How is this different from our everyday experience of these aspects of life? And how does the experience of spirituality differ from common psychological concepts such as happiness, mental health, and quality of life? These unresolved issues have made several authors

question whether spirituality is actually a meaningful concept (Bash, 2004; Koenig, 2008; Saländer, 2012). Throughout this dissertation I will return to this discussion and will try to take a step closer toward a possible solution.

The dissertation's definition

What has become clear from the discussion above is that spirituality and religion are related but independent constructs and that spirituality can include religion, but that this is not necessarily so. After all, we found that people self-identify as either religious, spiritual, both, or neither, and that definitions of spirituality contain both religious and non-religious beliefs, experiences, values, and practices. We can also conclude that there are several returning elements in the definitions of spirituality: Spirituality is about a belief in and experience of connectedness with oneself, others, nature, and/or the transcendent, which provides meaning and purpose to life.

Therefore, throughout this dissertation I will use the definition of spirituality posed by de Jager Meezenbroek and colleagues (2012), who state that "spirituality is one's striving for and experience of connectedness with the essence of life" (p. 142). These authors postulate that people define the essence of life as something that lies within themselves (an inner essence), as their relationship with others and nature, or as something transcendent (God or a higher power). When people are connected to this essence of life they experience meaning in life, trust in oneself, acceptance of both the ups and downs of life, compassion and responsibility toward others, a relationship with nature, and/or transcendent experiences, and they engage in spiritual activities.

Nature or nurture?

There is not only debate about which beliefs, experiences, and practices are part of spirituality, but also about the origin of spirituality: Is spirituality innate or the product of social-environmental influences? In other words, can anybody become spiritual or is it genetically determined who does or does not develop a spiritual meaning system? Studies on heredity and on the relationship between spirituality and personality suggest that the answer is 'both'.

Bradshaw and Ellison (2008) found among 316 monozygotic and 278 dizygotic twins that genetics explained only 27% of the variance in religious salience, 29% of the variance in spiritual salience, and 42% of the variance in a person's propensity to seek guidance from religious or spiritual beliefs in daily life and to seek comfort through religious or spiritual practices.

Saroglou (2010) investigated the association between spirituality and personality in a meta-analysis of 71 samples from 19 countries. He found a modest, positive association of religiosity to Agreeableness ($r = .19$) and Conscientiousness ($r = .16$); a modest, positive association of spirituality to Agreeableness ($r = .21$), Conscientiousness ($r = .14$), Extraversion ($r = .14$), and Openness to experience ($r = .18$); and a modest, positive association of religious

fundamentalism to Agreeableness (r = .13) and Conscientiousness (r = .12), but a modest, negative association to Openness (r = -.21). According to Saroglou these associations suggest that spirituality and religion are the cultural expressions of a person's personality; of the fundamental human concern for personal and social stability and moral self-transcendence. The finding that spirituality, but not religiosity, is positively associated with Openness to experience, indicates that non-religious spirituality expresses the additional human need for playfulness, personal growth, and social change (Saroglou, 2010). This finding also highlights the independence, but relatedness of spirituality and religion.

The association of spirituality with genetics and personality implies that the importance of spirituality in one's life is rather stable. This is confirmed by Vaillant, Templeton, Ardelt, and Meyer (2008), who found that the childhood church attendance of 268 men was significantly associated with whether or not they were religiously involved in adulthood (defined as the level of religious service attendance, personal belief in God, self-rated level of involvement, and importance of religious participation). On the other hand, genetics and personality explain only a small proportion of the variance in religious/spiritual involvement, so there still seems to be room for change. Valliant and colleagues, indeed, found that 25% of the men reported an increase in the religious involvement and 26% reported a decrease.

To summarize, it seems that some people are more likely to develop a spiritual or a religious meaning system than are others, depending on their childhood exposure to spirituality and their personality. In this regard, Skrzypińska (2014) describes spirituality as a developmental process that starts with the construction of a cognitive scheme (beliefs, values, norms, etc.) through interaction with one's environment, which brings about and is altered by emotional, attitudinal, and behavioral response patterns and experiences that interact with personality. The development of this cognitive scheme and these response patterns is driven by our innate need for meaning and self-fulfillment. The presence of these schemes and patterns determines our view and experience of ourselves and of our lives.

Spirituality and cancer

Now that we have established through which lens we will view spirituality, we can explore why spirituality might be important when a person experiences cancer and why I have written this dissertation.

Cancer figures

Cancer is a common illness. In 2012 the worldwide risk of being diagnosed with cancer before the age of 75 was 18.5% (among men this was 21% and among women 16.4%) and the risk of dying from cancer before the age of 75 was 10.4% (12.7% among men and 8.4% among women; Ferlay et al., 2013). In the Netherlands, cancer is the number 1 cause of death, having caused 30.8% of the deaths in 2012. Luengo-Fernandez, Leal, Gray, and Sullivan (2013) calculated that in 2009 cancer cost the European Union €126 billion, which translates to €102 per citizen. These costs are not only due to health care, which accounted for 40% of the costs,

but also due to productivity losses because of early death, lost working days, and informal care costs. So, even though cancer incidence and mortality have been on a steady decline over the past 25 years (Ferlay et al., 2013), they still form a major (economic) problem for the world population, especially in the developed countries.

Distress

To many people the diagnosis and treatment of cancer are highly stressful experiences, because these events bring about changes in, for example, daily routines, financial burden, physical and mental health, and expectations about the future. Although most people with cancer adjust well to these changes, a substantial proportion is not able to cope adequately with this situation and develops clinically elevated levels of mood disturbance. Within oncological and hematological settings a pooled prevalence of 18.5% for clinical depression, 19.4% for adjustment disorder, and 10.3% for anxiety disorder has been reported, after exclusion of studies that used convenience samples (Mitchell et al., 2011). The prevalence of any mood disorder was 38.2%. Based on a systematic literature review among outpatients with cancer, the prevalence of clinical depression was found to be 5% to 16% (Walker et al., 2013). Krebber and colleagues (2014) report a pooled prevalence of depression of 14% when assessed with a diagnostic interview and of 7% to 24% when assessed with self-report measures.

Mood disturbances seem to be most severe during the acute phase of illness (diagnosis and active treatment). Krebber and colleagues (2014) found that the prevalence of depression was 14% to 27% during the acute phase of illness, 9% to 21% during the first year after treatment, and 8% to 15% afterwards. Compared to healthy controls, the prevalence of depression was highest among people who had been diagnosed with cancer less than 2 years previously and lowest among patients who had been diagnosed more than 10 years previously (Mitchell, Ferguson, Gill, Paul, & Symonds, 2013). In contrast, the prevalence of anxiety seemed to increase with time since diagnosis.

These findings suggest that people with cancer experience different problems in adjustment over time. Henselmans, Coyne, Sanderman, de Vries, and Ranchor (2009) found that anxiety was most prevalent right after diagnosis and after surgery, while non-specific distress was most prevalent after surgery and up to 6 months after the end of treatment. The patients recovered relatively quickly: Compared to healthy controls, the women with breast cancer reported elevated levels of depression, anxiety, and non-specific distress until the end of the treatment, but no longer thereafter.

Although the average level of mood disturbances declines over time, recent studies suggest that there is a subgroup that remains highly distressed for years after the diagnosis of cancer. Dunn and colleagues (2012) found that 30.4% of patients with breast, prostate, lung, or brain cancer, and their family caregivers reported chronically elevated levels of anxiety and depression between the start of radiotherapy and four months after completion of the treatment. Among women with breast cancer 12% to 30% seem to experience chronically

elevated levels of psychological distress until six years after diagnosis (Helgeson, Snyder, & Seltman, 2004; Henselmans, Helgeson, Seltman, & de Vries, 2010; Lam et al., 2010, 2013; Lam, Shing, Bonanno, Mancini, & Fielding, 2012). The chronically distressed women in the study by Lam and colleagues (2010) also reported poorer family relationships, self-image, appearance, and sexuality, and more intrusive thoughts, hyper-arousal symptoms, and avoidant thoughts six years after surgery (Lam et al., 2012).

These studies have also examined which factors may distinguish between the patients who show resilience – the ability to maintain or regain their mental health (Stewart & Yuen, 2011) – and those who are chronically distressed. Although Dunn and colleagues (2012) and Lam and colleagues (2010, 2012) found that the patients reporting chronically high distress were more likely to be younger, to not be married, to have lower physical functioning, and to report more distress from physical symptoms, this was not confirmed in other studies (Dunn et al., 2011; Helgeson et al., 2004; Henselmans et al., 2010; Lam et al., 2013). A systematic literature review revealed that most studies did not demonstrate a relationship between socio-demographic factors and mood disturbance, but that 36 of 42 (mostly cross-sectional) studies did find a relationship between physical symptoms or functional impairments and mood disturbance (Garssen & Visser, unpublished). Interestingly, Bardwell and colleagues (2006) report that social support, social burden, and optimism reduced the negative impact of physical symptoms on depression. This suggests that psychological factors can have a large effect on the resilience of people with cancer. The studies comparing the resilient patients to the chronically distressed patients indeed found that the groups differed on several psychological factors; trait anxiety (Dunn et al., 2011, 2012), self-esteem, positive body image, personal control, illness uncertainty, perceived availability of social support, experiences of failed social support (Helgeson et al., 2004), sense of mastery (Henselmans et al., 2010), optimism, and cancer-related rumination (Lam et al., 2010, 2013, 2012). These factors are rather stable personal characteristics, suggesting that the people with cancer who are chronically distressed are more susceptible to negative mood even before the diagnosis of cancer. This is supported by the findings in our own review that neuroticism, pessimism, optimism, and a history of mood disturbance were most consistently related to long-term distress in people with cancer (Garssen & Visser, unpublished).

Spirituality as a coping resource

Another factor that may contribute to the resilience of a person with cancer is spirituality. We have seen previously that spiritual involvement can be a rather stable personal characteristic. In addition, people with cancer often indicate that their religious beliefs are an invaluable resource for strength, comfort, and meaning in their illness (Albaugh, 2003; Ardelt, Ai, & Eichenberger, 2008; Gall & Cornblat, 2002; Swinton, Bain, Ingram, & Heys, 2011; Trevino, Archambault, Schuster, Hilgeman, & Moye, 2011). Indeed, as we will see in chapter 2, numerous studies have found that spirituality is positively associated with mental health,

well-being, quality of life, and positive affect among people with cancer, and that it is negatively associated with distress, depression, and anxiety.

But why might spirituality be important when facing cancer? Several mechanisms have been identified to explain the beneficial effects of religious beliefs and practices on mental health, such as social support, hope, optimism, self-esteem, sense of control, and coping by positive (re)appraisal (Koenig, 2012; Levin, 2010). However, it is unclear whether these mechanisms can also account for the positive relationship between non-religious spirituality and mental health. Below, I will briefly discuss three of the most researched mechanisms that are also the most relevant to this dissertation: social support, optimism, and approach-oriented coping.

Social support

People who are spiritually involved may adjust well to the diagnosis and treatment of cancer, because they experience social support from others with the same beliefs. There seems to be a robust relationship between religious involvement and greater social support (McCullough et al., 2001). In addition, McCullough and colleagues found that greater religiousness or greater similarity in religious background between spouses are associated with greater marital satisfaction or marital stability. Social support and marital satisfaction have consistently been related to improved quality of life (Helgeson, 2003; Holt-Lunstad, Birmingham, & Jones, 2008; Pinquart & Sörensen, 2000; Thoits, 2011). Indeed, social support seems to mediate the relationship between spirituality and quality of life in various populations (Howsepian & Merluzzi, 2009; Lim & Yi, 2009; Salsman, Brown, Brechting, & Carlson, 2005). However, such effects are oftentimes only partial and in several studies religion was still associated with mental health after controlling for social support (Idler, 1987; Lim & Yi, 2009; Musick, Koenig, Hays, & Cohen, 1998; Sternthal, Williams, Musick, & Buck, 2010; Wink, Dillon, & Larsen, 2005).

An interesting study by Biegler and colleagues (2012) suggests that spirituality may also influence the relationship between social support and distress. They found that social support was only associated with lower stress and distress among men with urologic cancer who were highly religious, not among those who scored low on religiousness. Religiosity was not directly related to either social support or distress. The authors suggest that this finding may be explained by the availability of extra sources of social support to the religious men, such as the religious community. In this regard, Cohen, Yoon, and Johnstone (2009) found that congregational support, but not spiritual experiences or religious practices, was positively associated with mental health among 168 people with various medical conditions.

In addition, spirituality may offer a very particular type of support, namely the support received from God, saints, or some other type of Higher Power. Maton (1989) observed that experiencing spiritual support (defined as experiencing God's love and caring, experiencing a close relationship with God, and considering religious faith central to one's coping) was negatively associated to depression and positively associated to self-esteem among bereaved parents and college students who experienced many life events,

but not among those who experienced few life events. This effect remained after controlling for several other sources of support. Studies on religious coping have shown that people regularly seek spiritual support when dealing with serious life events such as cancer (Ai, Tice, Peterson, & Huang, 2005; Gall, Guirguis-Younger, Charbonneau, & Florack, 2009; Mackenzie, Rajagopal, Meibohm, & Lavizzo-Mourey, 2000). However, in the study by Gall and colleagues, the use of spiritual support coping was not associated with psychological adjustment to breast cancer over a 2-year period after breast cancer surgery. Ai and colleagues (2005) report that among college students, after the attacks on the USA on September 9, 2001, spiritual support was only indirectly associated with distress through positive attitude.

Optimism

The association of spirituality with positive attitudes or dispositional optimism may be another explanation for the importance of spirituality when facing cancer. Dispositional optimism has shown a rather robust, substantial relationship with less negative affectivity, particularly depression, (Andersson, 1996; Carver et al., 2005; Fournier, Ridder, & Bensing, 2002) and spirituality has been associated with more optimism or a positive attitude (Ai et al., 2005; Ciarrocchi, Dy-Liacco, & Deneke, 2008; Koenig, 2012; Mattis, Fontenot, Hatcher-Kay, Grayman, & Beale, 2004).

Several studies have demonstrated that optimism or positive attitude mediates the relationship between spirituality and mental health (Chan, Rhodes, & Pérez, 2012; Ciarrocchi & Deneke, 2005; Gall, Kristjansson, Charbonneau, & Florack, 2009; Ho, Cheung, & Cheung, 2010; Salsman et al., 2005). It has been suggested that the meaning that spiritual beliefs offer to life events promotes a sense of optimism, which in turn increases mental health. This is supported by the finding of Lee, Cohen, Edgar, Laizner, and Gagnon (2006) that a meaning-making intervention led to a small, but significant increase in optimism among patients with breast cancer or colorectal cancer compared to a control group. On the other hand, Ju, Shin, Kim, Hyun, and Park (2013) found that meaning in life mediated the relationship between optimism and happiness among older adults, suggesting that optimism increases meaning in life.

Not all aspects of spirituality seem to be equally strongly related to optimism. Mattis and colleagues (2004) found among African-American adults that subjective spirituality and experiencing a positive relationship with God were positively associated with optimism, whereas subjective spirituality and not experiencing a negative relationship with God were negatively related with pessimism. Early religious involvement, subjective religiosity, and frequency of church attendance were neither related to optimism nor to pessimism. Similarly, Ciarrocchi and colleagues (2008) observed among a convenience sample of ethnically diverse American adults that - while controlling for personality - content aspects of religiosity (connectedness with a higher power, altruistic commitment from religion, daily spiritual experiences, values/beliefs, and meaning in life) were more consistently related with optimism and hope than functional aspects of religiosity (religious practices, positive and

negative religious coping, congregational support, self-designation as a spiritual or religious person, organized religiousness, and religious denomination).

Approach–oriented coping

Qualitative studies have found that patients often describe spirituality as a source of positive meaning to their illness experience; it helps them to reappraise the illness as 'meant to be' and 'part of God's plan', instead of a disruptive and negative event. Such positive reappraisal coping helps the patients to actively accept the illness and to find hope (Daaleman, Cobb, & Frey, 2001; Gall & Cornblat, 2002; Molzahn et al., 2012).

Positive reframing or reappraisal is considered to be an approach-oriented coping strategy. In an early meta-analysis, Suls and Fletcher (1985) determined that avoidance-oriented strategies (for example, distraction, denial, cognitive avoidance) and approach-oriented strategies (for example, problem-solving, seeking social support, positive reappraisal) had similar positive associations with psychological mental health. However, when distinguishing short-term or long-term effects, they found that avoidance strategies (especially distraction or cognitive avoidance) were somewhat more effective up to seven days after the stressor had occurred, whereas approach-oriented strategies were more effective two weeks or longer after the occurrence of the stressor. This difference in effectiveness has been confirmed in several studies since then (Taylor & Stanton, 2007). Spirituality seems to be related to more use of approach-oriented coping strategies - especially active coping, positive reappraisal, emotional expression, and seeking social support - which may also partially explain why it is positively associated with mental health (Canada et al., 2006; Meyer, Altmaier, & Burns, 1992; Unantenne, Warren, Canaway, & Manderson, 2013; Vespa, Jacobsen, Spazzafumo, & Balducci, 2011).

In addition, spirituality offers its own unique ways of coping. Thus far, research has focused on spiritual coping strategies in a traditionally religious context. Most often these religious coping strategies are divided into positive strategies and negative strategies. Positive strategies reflect a secure relationship with God, a sense of meaning in life, and a sense of connectedness with others. Negative strategies, on the other hand, reflect an unstable relationship with God, difficulty finding meaning in life, and a low sense of control (Pargament, Koenig, & Perez, 2000; Pargament, Smith, Koenig, & Perez, 1998). A meta-analysis of 49 studies showed that positive religious coping is positively related with mental health and negatively related with distress during stressful life events, whereas negative religious coping was not related to mental health and negatively related to distress (Ano & Vasconcelles, 2005). In the context of cancer, however, the advantages or disadvantages of turning to religious beliefs and practices to cope remain unclear (Lavery & O'Hea, 2010; Thuné-Boyle, Stygall, Keshtgar, & Newman, 2006). Nevertheless, it does seem that negative religious coping is more consistently related to poor adjustment to cancer than is positive religious coping to good adjustment. Sherman, Simonton, Latif, Spohn, and Tricot (2005) suggest that this is, because negative coping represents a change in one's view rather than

the maintenance of a typical coping response. In other words, negative religious coping reflects the experience of incongruence between the event and the expectations that the person had of life.

This suggestion is in line with the proposition of several authors that spirituality acts as a (part of a person's) meaning system (Daaleman et al., 2001; James & Wells, 2003; Park, 2007; Skrzypińska, 2014). A meaning system is a cognitive unity of beliefs, attitudes, values, and norms that each individual develops across his or her personal history. Through this meaning system the person identifies himself, ascribes meaning to his life, and attains a sense of certainty (van Uden, 1985). When a person is diagnosed with cancer, this event may violate some of the fundamental beliefs within the meaning system of the person, such as the belief that God does not allow bad things to happen to His children. These expectancy violations can trigger negative emotions and the need to reestablish meaning by looking for social cohesion in one's interpretation of the event and, thereby, adjusting the meaning of the situation, adjusting elements of the meaning system, or finding meaning in other aspects of life that have not been violated (Heine, Proulx, & Vohs, 2006; Jeserich, 2014). Negative religious coping reflects this search for new meaning: For example, the negative religious coping strategy 'punishing God reappraisal' reflects an adjustment of the situational meaning as punishment by God, the strategy 'reappraising God's power' reflects an adjustment of global beliefs about God, and the strategy 'passive religious deferral' reflects handing over control of the situation to God and trying to find consolation elsewhere. In contrast, positive religious coping reflects a match between the situational meaning and the spiritual meaning system, which creates confidence in the comprehensibility, manageability and meaningfulness of life, and is accompanied by positive emotions (Jeserich, 2014).

This study

In the studies described in this dissertation I address a number of important limitations to current research on the relationship of spirituality to mental health in general, and to psychological adjustment to cancer in particular. First, most studies have used a cross-sectional research design, which precludes conclusions on the direction and mechanisms of the relationship (Chapter 2). Second, most studies have focused on narrow indicators of religious spirituality, such as frequency of prayer, church attendance, or importance of religion/spirituality in one's life, whereas spirituality is a multidimensional concept that is not restricted to religion (Chapters 5 and 8). Third, because spirituality is often defined in terms of mental health, many studies have assessed spirituality with instruments that have overlapping content with the outcome measures, which may have artificially inflated the found relationship (Chapters 2, 3 and 4). Fourth, most studies on adjustment to cancer have been conducted among women with breast cancer, which limits our understanding of the importance of spirituality for people with other types of cancer (Chapters 2, 6, and 7). Fifth, many studies on adjustment to cancer have included cancer survivors, whereas spirituality

may be more important during the first two years after the diagnosis of cancer, because this period has been found to be most stressful (Chapters 6 and 7).

With this dissertation I hope to expand our understanding about how and why spirituality is associated with adjustment to cancer. With this knowledge, care professionals may be better able to understand and to intervene in the process of adjustment of patients with cancer who struggle with chronically elevated levels of distress, by harnessing the (spiritual) strengths of the person and offering alternatives for their weaknesses.

This dissertation consists of two parts. In part 1 I investigate the operationalization of spirituality, whereas in part 2 I examine the relationship between spirituality and adjustment to cancer. I outline the chapters in more detail below.

Part 1

In chapters 2, 3, and 4 I address the issue of conceptual overlap between measures of spirituality and mental health. In chapter 2 I do this by discussing the state of knowledge on the relationship between spirituality and psychological adjustment to cancer up until the year 2009. Due to content overlap between the measurement instruments for spirituality and adjustment, we know little about the true nature of this relationship.

Therefore, in chapter 3 I examine the content overlap between the spirituality and well-being questionnaires that we have used in our own research. After all, we would not want to make the same mistake as the researchers before us.

In chapter 4 I discuss other measures of spirituality in light of the conceptual overlap, in order to come to an advise about which questionnaires may be most appropriate for use in future studies on the effect of spirituality on mental health.

Part 2

After having established in part 1 what spirituality is and is not, I investigate in chapters 5, 6, 7, and 8 whether and how spirituality is related to adjustment to cancer. In chapter 5 I discuss the state of knowledge up until 2014 on the moderating and direct, prospective influence of spirituality on mental health in various types of populations. However, few of these studies have included cancer patients and most have assessed religious spirituality.

Therefore, in chapter 6 I discuss two studies that focus on whether non-religious spirituality influences the adjustment to cancer-related stressors. The first study uses a cross-sectional research design. I investigate among 210 people with cancer, who were treated with curative or palliative intent, whether spirituality moderates the relationship of pain and fatigue to well-being and distress. The second study uses a longitudinal research design. It concerns a one-year mixed-methods study among 383 people with various types of cancer, who were treated for this illness with curative intent. I investigate during two six-months periods after the start of cancer treatment whether spirituality moderates the effect of changes in pain, fatigue, and perceived life threat on well-being and distress.

In chapter 7 I take a different approach to the measurement of spirituality, to further investigate its direct effect on adjustment to cancer. Instead of examining various aspects of spirituality, I take the participants' self-identification as a spiritual and/or religious person as the measure of spirituality. I investigate among the 383 people with cancer encountered in chapter 6, study 2, whether the levels of well-being and distress develop differently between people with these four types of spirituality and whether any differences in adjustment may be explained by differences in the presence of other sources of resilience.

In chapter 8 I explore in a qualitative study among 10 highly spiritual people with cancer how they describe the role that their spirituality has played in the adjustment to the diagnosis and treatment of cancer, to gain a better understanding of this relationship.

Finally, in chapter 9 I will wrap things up by indicating what we can learn from all that has been discussed in this dissertation, what the shortcomings of my studies are, and what directions future research on spirituality and adjustment to cancer might take.

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Part 1

Defining spirituality

2.

Spirituality and well–being in cancer patients: A review[1]

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Abstract

Cancer places many demands on the patient and threatens the person's sense of meaning to life. It has been shown that cancer patients use their spirituality to cope with these experiences. The present literature review summarizes the research findings on the relationship between spirituality and emotional well-being in cancer patients. Special attention is given to the strength of the research findings. A literature search was performed in PubMed and Web of Science. Spirituality does not necessarily coincide with religiosity. Therefore, studies were excluded that focused on religiosity. Forty publications met the inclusion criteria: Twenty-seven studies that investigated the relationship between spirituality and well-being, and thirteen publications that explored the relationship between meaning in life and well-being. The majority of the cross-sectional studies (31 of 36) found a positive association between spirituality and well-being. The four studies with a longitudinal design showed mixed results. The significance of the findings is challenged, because most spirituality questionnaires contain several items that directly refer to emotional well-being. Despite that the majority of the studies concluded that spirituality was associated with higher well-being no definitive conclusions on this relationship can be drawn due to major methodological shortcomings of these studies. Longitudinal research utilizing spirituality and well-being measures that do not overlap in content is recommended.

Introduction

Cancer places considerable demands on the patient such as having to deal with physical symptoms, treatment side effects, changes in relationships, changes in self-image, the unpredictability of disease, uncertainty about the future, unmet expectations about recovery, and vulnerability to recurrence of disease (Fernsler, Klemm, & Miller, 1999). Cancer also threatens the patient's sense of meaning to life and of connectedness with him/herself and the environment (Tulls Halstead & Hull, 2001). Tulls Halstead and Hull (2001) described how female cancer patients struggled with a number of paradoxes: (1) They viewed themselves as healthy but were diagnosed with a life-threatening illness; (2) they were hopeful about being cured, but also feared recurrence; (3) they found meaning in a belief-system, but this was repeatedly challenged by the diagnosis; (4) they looked forward to the future, but dreaded the unpleasant treatment and possible mortality that lay ahead. Many patients suffer from these fears and uncertainties (Murray, Kendall, Boyd, Worth, & Benton, 2004; White, 2004), and they may feel the need for help to deal with these fears, to have a positive perspective, to give and receive love, and to relate to God or a higher being (Johnston Taylor, 2006). Many studies have shown that spirituality or religion is employed by (cancer) patients to fulfil such needs and to cope with the illness experience (Mytko & Knight, 1999; Thomas & Retsas, 1999; Tulls Halstead & Hull, 2001; Weaver & Flannelly, 2004). The role of spirituality in the adjustment to disease has been studied both in cross-sectional and longitudinal studies among various patient populations (e.g., amputees, HIV/AIDS patients, hematologic cancer patients). These studies have indicated that spirituality/religiosity is associated with better quality of life and well-being and less distress (Chibnall, Videen, Duckro, & Miller, 2002; Kim, Heinemann, Bode, Sliwa, & King, 2000; Nelson, Rosenfeld, Breitbart, & Galietta, 2002; Riley et al., 1998; Rippentrop, Altmaier, & Burns, 2006).

Spirituality has been defined in many ways, such as "a search for relatedness and meaning" (Girardin, 2000, p. 270) and "a subjective experience of the sacred" (Vaughan, 1991, p. 105). Spirituality differs from religion in that religion places spirituality within the context of the beliefs, values, and practices of an organized institution (Belzen, 2004; Mytko & Knight, 1999). So, religion can be considered a specific form of spirituality. In line with the definition of Girardin, we define spirituality as "one's striving for and experience of a connection with the essence of life" of which the experiences of meaning in life and connectedness are central elements (Jager Meezenbroek et al., 2012, p.142).

In this review both cross-sectional and longitudinal studies on the relationship between spirituality and emotional well-being, hereafter referred to as well-being, in cancer patients will be summarized. Special attention will be given to the methodological problems that weaken the conclusions of the studies summarized. Previous reviews on spirituality and well-being in cancer patients contain many studies that have defined spirituality in religious terms (Jenkins & Pargament, 1995; Lin & BauerWu, 2003; Ramondetta & Sills, 2004; Stefanek, McDonald, & Hess, 2005; Weaver & Flannelly, 2004). This review distinguishes itself from older reviews by focusing on studies that employed a broad, universal, definition of spirituality.

Methods

A literature search was performed in PubMed and Web of Science with the following keywords: cancer/oncolog* AND spiritual*/meaning AND quality of life/well-being/coping/ distress/depression/ anxiety/adjustment/social support. No restrictions were made as to the publication year. Besides spirituality, the term meaning was included in the search because meaning in life is regarded as the essential component of spirituality. The search resulted in a total of 7369 hits (including doubles). After reading the titles and abstracts 160 articles were initially selected, but after further reading 40 studies that fulfilled the inclusion criteria were included in the review.

Studies were selected if they (1) included a sample of cancer patients aged 18 or older, (2) had psychosocial outcome measures (e.g., quality of life, well-being, distress, depression, anxiety, coping, adjustment, experienced quality of social support), (3) were quantitative, and (4) were published in the Dutch or English language. Conference reports and meeting abstracts were included in this review if the questionnaires that had been used were specified and relevant statistical coefficients were reported. Because of the broad and universal definition of spirituality employed here studies that used spirituality questionnaires mainly referring to religious concepts, such as 'God' or 'prayer', were excluded. This lead to the exclusion of nine studies: one study that used the Index of Core Spiritual Experiences (INSPIRIT; Kass, Friedman, Leserman, Zuttermeister, & Benson, 1991), two studies that applied the SpREUK (Büssing, Matthiessen, & Ostermann, 2005), and six studies that used the Systems of Beliefs Inventory (SBI; Kash et al., 1995).

Results

The results are displayed in Table 2.1. The relationship between spirituality and well-being was addressed in 27 studies, which will be discussed first. Subsequently, we will focus on the 13 studies on the relationship between meaning in life and well-being. Well-being was defined as the absence of distress, depression, anxiety, hopelessness, desire for hastened death, suicidal ideation, and/or the presence of quality of life, psychological well-being, mental health, happiness, adjustment, or social functioning.

The relationship between spirituality and well–being

Twenty-six cross-sectional and one longitudinal study have been published about the relationship between spirituality and well-being. Twenty-three cross-sectional studies found a positive relationship between spirituality and well-being, which means that more spirituality involvement was associated with more well-being (Borman, 1999; Brady, Peterman, Fitchett, Mo, & Cella, 1999; Cotton, Levine, Fitzpatrick, Dold, & Targ, 1999; Dapueto, Servente, Francolino, & Hahn, 2005; Dye et al., 1999; Edmondson, Park, Blank, Fenster, & Mills, 2008; Krupski et al., 2006; Laubmeier, Zakowski, & Bair, 2004; Leak, Hu, & King, 2008; McClain, Rosenfeld, & Breitbart, 2003; McClain-Jacobson et al., 2004; McCoubrie & Davies, 2006;

Montavon Kaczorowski, 1989; Morgan, Gaston-Johansson, & Mock, 2006; Perkins et al., 2007; Prince-Paul, 2008; Rodin et al., 2007, 2009; Romero et al., 2006; Salsman, Yost, West, & Cella, 2008; Schnoll, Harlow, & Brower, 2000; Wassel Zavala, Maliski, Kwan, Fink, & Litwin, 2009; Whitford, Olver, & Peterson, 2008). Fifteen of these studies controlled for socio-demographic factors and cancer-related factors and reported that the relationship persisted (Borman, 1999; Brady et al., 1999; Cotton et al., 1999; Dye et al., 1999; Krupski et al., 2006; McClain et al., 2003; McClain-Jacobson et al., 2004; Montavon Kaczorowski, 1989; Morgan et al., 2006; Perkins et al., 2007; Prince-Paul, 2008; Romero et al., 2006; Salsman et al., 2008; Schnoll et al., 2000; Wassel Zavala et al., 2009). This suggests that the relationship between spirituality and well-being is not dependent on a third factor such as age or physical symptoms. Three studies failed to find a relationship between spirituality and well-being (Boscaglia, Clarke, Jobling, & Quinn, 2005; Mystakidou et al., 2007; Richardson Gibson & Parker, 2003). One of these did identify an indirect positive effect of spirituality on psychological well-being through increased hope, but spirituality was not directly associated with psychological well-being (Richardson Gibson & Parker, 2003).

The only longitudinal study investigated the relationship between spirituality and hopelessness. It was found that spirituality was associated with decreased hopelessness at a cross-sectional level, but that spirituality at baseline (3 months after the diagnosis of a recurrence) did not predict hopelessness one year later (Brothers, Purnell, Crespin, & Andersen, 2006).

Three studies demonstrated that spirituality may influence the relationship between other predictors and well-being. Brady and colleagues showed that patients scoring high on spirituality reported high levels of enjoyment of life, regardless of their level of pain or fatigue (Brady et al., 1999). In patients low on spirituality, joy in life was dependent on their level of somatic symptoms. However, a newer study could not confirm this interaction model, although they did find a main effect of spirituality on joy in life/quality of life (Whitford et al., 2008). McClain et al. (2003) reported that depression was not associated with desire for hastened death among palliative care patients scoring high on spirituality, whereas depression was associated with the desire for hastened death among patients low on spirituality.

In 14 of the 27 studies a distinction was made between a horizontal/existential dimension of spirituality (a feeling of meaning, peace, and connectedness to the self and others) and a vertical/religious dimension of spirituality (the belief in and experience of connectedness with a higher power) (Borman, 1999; Brady et al., 1999; Cotton et al., 1999; Edmondson et al., 2008; Krupski et al., 2006; Laubmeier et al., 2004; McClain et al., 2003; McClain-Jacobson et al., 2004; McCoubrie & Davies, 2006; Montavon Kaczorowski, 1989; Rodin et al., 2007; Salsman et al., 2008; Wassel Zavala et al., 2009; Whitford et al., 2008). The horizontal dimension of spirituality appeared to be more strongly related with well-being than the vertical dimension in all studies. In fact, four of these 14 publications reported that only the horizontal dimension of spirituality was related with quality of life, not the vertical

dimension (Krupski et al., 2006; Laubmeier et al., 2004; McCoubrie & Davies, 2006; Wassel Zavala et al., 2009). The relationship between the vertical dimension of spirituality and mental health even became negative when controlling for the horizontal dimension of spirituality in a study by Edmondson and colleagues (2008).

The relationship between meaning in life and well–being

Eleven cross-sectional and two longitudinal studies investigated the relationship between meaning in life and well-being. Additionally, two cross-sectional studies explored the relationship between search for meaning and well-being. Nine cross-sectional studies found that meaning in life was associated with increased well-being (Bauer-Wu & Farran, 2005; Fleer, Hoekstra, Sleijfer, Tuinman, & Hoekstra-Weebers, 2006; Jim & Andersen, 2007; Jim, Richardson, Goden-Kreutz, & Andersen, 2006; Johnson Vickberg et al., 2001; Johnson Vickberg, Bovbjerg, DuHamel, Currie, & Redd, 2000; Lethborg, Aranda, Cox, & Kissane, 2007; Park, Edmondson, Fenster, & Blank, 2008; Simonelli, Fowler, Maxwell, & Andersen, 2008). Six of these studies reported that the relationship persisted after controlling for socio-demographic and cancer-related factors (Fleer et al., 2006; Jim & Andersen, 2007; Johnson Vickberg et al., 2001, 2000; Lethborg et al., 2007; Simonelli et al., 2008).

Two studies investigated the relationship between meaning in life and well-being using a longitudinal design. Jim and Andersen (2007) demonstrated that meaning in life was associated with less distress six months later. They also found that meaning in life mediated the relationship between social and physical functioning on distress, both in a longitudinal and in a cross-sectional study. Social functioning and physical functioning were associated with increased meaning in life, which in turn was associated with less distress. In a study by Park and colleagues (2008) participants who experienced meaning in life reported higher well-being cross-sectionally, as in the nine studies mentioned above. However, meaning in life at baseline (approximately 2.5 years after diagnosis) influenced well-being one year later only through its relationship with just-world violations. Most importantly, patients who felt that their lives were meaningful after diagnosis, experienced more just-world violations one year later, which increased their repetitive thoughts and in turn decreased their psychological well-being.

One study found that meaning in life influenced the relationship between intrusive thoughts and distress: Intrusive thoughts were only related with more distress among patients who experienced little meaning in life, not among those who experienced much meaning in life (Johnson Vickberg et al., 2000). Another study reported on a mediation effect of meaning of life on the relationship between physical symptoms and depression: Patients who experienced many physical symptoms viewed their lives as less meaningful and thus were more depressed (Simonelli et al., 2008). The reverse model fitted the data less well, indicating that it is less likely that those who experienced many physical symptoms were more depressed and thereby experienced less meaning in life.

Finally, Ruff Dirksen (1995) and Roberts, Lepore, and Helgeson (2006) investigated the relationship between search for meaning and well-being. Search for meaning is distinct from meaning in life, because it represents the process toward the experience of meaning in life. A strong tendency to search for personal meaning in an event may indicate uncertainty or despair, whereas the experience of meaning in life may indicate hopefulness and certainty. Therefore, search for meaning and meaning in life may not be related to well-being in the same way. In her cross-sectional study Ruff Dirksen found that search for meaning was not related with life satisfaction among survivors of malignant melanoma. Roberts, on the other hand, found that search for meaning was related with less mental and physical functioning, but more social support at a cross-sectional level.

Table 2.1 Summary of studies on spirituality and well–being in cancer patients

First author, year	N	Type of cancer	Questionnaire	Outcome in expected direction Yes/No
		Spirituality		
Cross-sectional				
Brady, 1999	1337	Several	FACIT-sp	Yes
Borman, 1999	75	Several	Rush Spiritual Beliefs Module	Yes
Boscaglia, 2005	100	Gynecological	SIBS	No
Cotton, 1999	142	Breast	FACIT-sp	Yes
Dapueto, 2005	309	Several	FACIT-sp	Yes
Dye, 1999	683	Several	FACIT-sp	Yes
Edmondson, 2008	237	Several	FACIT-sp	Yes
Krupski, 2006	287	Prostate	FACIT-sp	Yes
Laubmeier, 2004	95	Several	SWBS	Yes
Leak, 2008	30	Breast	SPS	Yes
McClain, 2003	160	Several	FACIT-sp	Yes
McClain, 2004	276	Several	FACIT-sp	Yes
McCoubrie, 2006	85	Several	SWBS	Yes
Montavon, 1989	114	Several	SWBS	Yes
Morgan, 2006	11	Breast	FACIT-sp	Yes
Mystakidou, 2007	82	Several	SIBS	No
Perkins, 2007	127	Breast	FACIT-sp	Yes
Prince-Paul, 2008	50	Several	JAREL	Yes
Richardson, 2003	162	Breast	SPS	No
Rodin, 2007	326	Gastro-intestinal, lung	FACIT-sp	Yes
Rodin, 2008	406	Gastro-intestinal, lung	FACIT-sp	Yes

(Table 2.1 continued)

Romero, 2006	81	Breast	"How spiritual/religious do you consider yourself?"	Yes
Salsman, 2008	826	Colorectal	FACIT-sp	Yes
Schnoll, 2000	83	Several	SWBS	Yes
Wassel, 2008	86	Prostate	FACIT-sp	Yes
Whitford, 2008	449	Several	FACIT-sp	Yes
Longitudinal prospective				
Brothers, 2006	48	Breast	FACIT-sp	No
		Meaning in life		
Cross-sectional				
Bauer-Wu, 2005	39	Breast	PMI	Yes
Fleer, 2006	354	Testicular	LRI	Yes
Jim, 2006	167	Breast	MiLS	Yes
Jim, 2007, Study 1	420	Several	MiLS	Yes
Johnson, 2000	61	Breast	PMI	Yes
Johnson, 2001	85	Leukemia	PMI	Yes
Lethborg, 2007	100	Several	PMI	Yes
Ruff, 1995	31	Malignant melanoma	SMS	No
Simonelli, 2008	260	Gynecological	MiLS	Yes
Longitudinal prospective				
Jim, 2007, Study 2	167	Breast	MiLS	Yes
Park, 2008	172	Several	PPMS	Yes
Roberts, 2006	89	Prostate	"How often have you found yourself searching to make sense of you illness?" and "how often have you found yourself wondering why you got cancer or asking 'Why Me'"	No

Note FACIT-sp = Functional Assessment of Chronic Illness Therapy – spiritual well-being (Brady et al., 1999), SIBS = Spiritual Involvement and Belief Scale (Hatch, Burg, Naberhaus, & Hellmich, 1998), SPS = Spiritual Perspective Scale (Reed, 1987), SWBS = Spiritual Well-Being Scale (Ellison, 1983), PMI = Personal Meaning Index (Reker, 1992), SMS = Search for Meaning Scale (Ruff Dirksen, 1995), LRI = Life Regard Index (Debats, 1990), MiLS = Meaning in Life Scale (Jim, Purnell, Richardson, Goden-Kreutz, & Andersen, 2006), PPMS = Perceived Personal Meaning Scale (Wong, 1998).

The significance of the findings

The majority of cross-sectional studies have found that spirituality and meaning in life are positively related with well-being. However, the longitudinal studies did not consistently reveal such a relationship.

Although this empirical evidence for the role of spirituality in well-being seems overwhelming, several methodological weaknesses have to be addressed that hinder a definite conclusion. Thirty-six of the 40 studies reviewed in this article used a cross-sectional design. Therefore, no definitive conclusion can be drawn about causality; do patients feel better because they are spiritual or are they spiritual because they feel better? Are both spirituality and well-being related to a third factor (e.g., personality)? Experimental research has been conducted into the mechanisms through which spirituality or religiosity might cause better health and psychosocial well-being. For example, typical spiritual/religious practices such as meditation and prayer have been found to be associated with decreased blood pressure, increased immune functioning, increased heart rate variability, and – what is most important in this context - a general sense of calmness and relaxation (Bernardi et al., 2001; Berntson, Norman, Hawkley, & Cacioppo, 2008; Carlson, Speca, Faris, & Patel, 2007; Seeman, Dubin, & Seeman, 2003). On the other hand, it is well imaginable that it are mainly the patients who feel better who experience connectedness and meaning in life. These patients may be more active, for example go for walks in nature and visit friends, which can increase their experiences of connectedness. Also, they may be more capable of maintaining the activities that give meaning to their lives. Danhauer, Crawford, Farmer, and Avis (2009) found that, although spirituality was related with higher well-being over a 6 month period, quality of life did not influence spirituality. Alternatively, both concepts could imply each other. Does experiencing meaning in life and feeling connected to other people, nature or a higher being always imply well-being and does a high level of well-being always imply the experience of meaning in life and connectedness? In our view the two concepts are not by definition related: one may experience meaning in life and connectedness in periods of sadness and anxiety. Longitudinal and experimental studies may yield insight about the causal relations, but the longitudinal studies in this review were inconsistent in their findings.

To demonstrate a relationship between spirituality and well-being it is of the utmost importance that the contents of questionnaires that are used to measure both concepts do not overlap. This is not always so. The spirituality questionnaires that are used most often, also in the studies reviewed here, are the Functional Assessment of Chronic Illness Therapy - spiritual well-being scale (FACIT-sp; Brady et al., 1999), the Spiritual Well-Being Scale (SWBS; Ellison, 1983), the Spiritual Involvement and Beliefs Scale (SIBS; Hatch, Burg, Naberhaus, & Hellmich, 1998), and the Spiritual Perspective Scale (SPS; Reed, 1987). The FACIT-sp, in particular the subscale Meaning/Peace, contains many items that directly refer to well-being. Thus it seems quite obvious that a high score on the FACIT-sp is associated with high well-being. Indeed, the 16 studies in this review that used the FACIT-sp without exception found a positive association between spirituality and well-being (Borman, 1999; Brady et al., 1999;

Cotton et al., 1999; Dapueto et al., 2005; Dye et al., 1999; Edmondson et al., 2008; Krupski et al., 2006; McClain et al., 2003; McClain-Jacobson et al., 2004; Morgan et al., 2006; Perkins et al., 2007; Rodin et al., 2007, 2009; Salsman et al., 2008; Wassel Zavala et al., 2009; Whitford et al., 2008). The SWBS consists of the two subscales Existential Well-Being and Religious Well-Being (EWB and RWB, respectively). Particularly the EWB subscale contains items that directly refer to well-being, such as "I feel that life is a positive experience" and "I feel very fulfilled and satisfied with life". Therefore, de Jager Meezenbroek and colleagues (2012) explicitly discourage the use of this subscale as a predictor of well-being. The four studies in this review that employed the SWBS all reported a positive association between spirituality and well-being and found that the EWB subscale was more strongly related with well-being than the RWB subscale (Laubmeier et al., 2004; McCoubrie & Davies, 2006; Montavon Kaczorowski, 1989; Schnoll et al., 2000). The SIBS hardly refers to positive or negative affect and where it does so it always refers to a spiritual mechanism by which such affect came about (e.g. "I find serenity by accepting things as they are"). Therefore, the SIBS and measures of well-being do not seem to be artificially associated due to item overlap. In fact, both studies in this review that used the SIBS did not find a relationship between spirituality and well-being (Boscaglia et al., 2005; Mystakidou et al., 2007). Finally, the SPS refers mainly to spiritual behaviors and beliefs. No reference is made to positive or negative affect so no obvious relationship with well-being may be expected. Both studies that applied the SPS found a positive relationship between spirituality and well-being (Richardson Gibson & Parker, 2003; Leak et al., 2008), although Richardson Gibson and Parker only found an indirect relationship through hope. Finally, one study applied the JAREL spiritual well-being scale (Hungelman, Kenkel-Rossi, Klassen, & Stollenwerk, 1996), which contains several items that directly refer to well-being, and in one publication participants were asked how spiritual they considered themselves to be.

The most frequently used questionnaires to assess meaning in life were the Personal Meaning Index of the Life Attitude Profile (PMI; Reker, 1992) and the Meaning in Life Scale (MiLS; Jim, Purnell, Richardson, Goden-Kreutz, & Andersen, 2006). The PMI consists of two subscales of the Life Attitude Profile, namely Purpose and Coherence. Only a few items refer to well-being (e.g. "In achieving life's goals, I have felt completely fulfilled" and "I have discovered a satisfying life purpose"). Therefore, an association with well-being does not seem to be artificial. The four studies in this review that used the PMI all reported a negative association between meaning in life and distress (Bauer-Wu & Farran, 2005; Johnson Vickberg et al., 2001, 2000; Lethborg et al., 2007). The MiLS does contain several items that refer to positive affect, such as "I feel peaceful", "I feel more fulfilled and satisfied with life", and "I find comfort in my faith and spiritual beliefs". Thus it is to be expected that this measure of meaning in life is related with well-being. Indeed, the three studies that used the MiLS all found a negative association between meaning in life and distress (Jim & Andersen, 2007; Jim, Richardson, et al., 2006; Simonelli et al., 2008). Other measures of meaning in life included the Life Regard

Index (Debats, 1990) and the Perceived Personal Meaning Scale (Wong, 1998). Both scales do not contain well-being items.

Discussion

In this review we have summarized studies on the relationship between spirituality, and its main component meaning in life, and emotional well-being in cancer patients. It may seem self-evident that spirituality contributed to well-being in cancer patients, because it is repeated so often. However, most studies in this field have used a cross-sectional design, which makes conclusions about a cause-and-effect relationship impossible. Also, many spirituality questionnaires include items referring to well-being, which artificially inflates the relationship. Of the 36 cross-sectional studies reviewed, 33 found a positive relationship between spirituality and well-being, 2 found no relationship, and 1 studied search for meaning. This relationship remained after controlling for socio-demographic and disease-related factors. However, 24 of the 33 studies used a spirituality questionnaire that contains well-being items, raising the possibility of an artificial relationship. Only three studies explored the longitudinal relationship between spirituality and well-being and one longitudinal study focused on search for meaning. The three studies on spirituality and well-being showed mixed findings: One found a direct positive relationship, one reported on an indirect relationship where spirituality was associated with less well-being, and one failed to find a relationship.

Spirituality is a multi-dimensional concept and its various aspects may be related differently to emotional well-being. Of the studies in this review, 13 studies examined the relationship of separate aspects of spirituality and well-being (Brady et al., 1999; Edmondson et al., 2008; Krupski et al., 2006; Laubmeier et al., 2004; McClain et al., 2003; McCoubrie & Davies, 2006; Montavon Kaczorowski, 1989; Rodin et al., 2007, 2009; Salsman et al., 2008; Schnoll et al., 2000; Wassel Zavala et al., 2009; Whitford et al., 2008). These studies all used the FACIT-Sp or the SWBS. Although the JAREL, SPS, and SIBS are also multidimensional scales, the studies that have used those questionnaires do not discuss the association of separate spirituality factors with well-being. Both the FACIT-Sp and the SWBS contain two dimensions that reflect the horizontal and vertical dimensions of spirituality. The horizontal dimension was more strongly related with well-being than the vertical dimension. In four studies the vertical dimension showed no relationship with well-being and in one study this relationship was even negative. Recently a three-factor solution for the FACIT-sp has been proposed, that contains a Meaning, Peace, and Faith subscale. The subscale Peace showed a somewhat stronger association with increased well-being than Meaning, while the Faith subscale was associated with decreased well-being (Canada, Murphy, Fitchett, Peterman, & Schover, 2008; Murphy et al., 2010). All in all, the knowledge about the specific character of the relationship between spirituality, and its aspects, and well-being is very limited.

Although our scientific skepticism questions the evidence about the causal relationship between spirituality and well-being, this does not undo the necessity to give

spirituality a place among the aspects of quality of life and in clinical care. Studies have indicated that patients struggle with spiritual needs which they would like to have addressed by their physician or nurse (Harrison, Young, Price, Butow, & Solomon, 2009; Johnston Taylor & Mamier, 2005; Johnston Taylor, 2006; King & Bushwick, 1994; Moadel et al., 1999). The current research on spirituality and well-being has shown that spirituality and well-being are closely related and perhaps inseparable. Therefore, it is important to address spiritual issues in health care. Perhaps nurses and physicians are not the persons best equipped to do so because of time restraints and difficulties in perceiving the spiritual needs in their patients (Kuuppelomäki, 2002; Mårtensson, Carlsson, & Lampic, 2008). Also, patients ranked physicians and nurses as the number three and four spiritual caregivers, after family members and friends (Farrar Highfield, 1992). Alternatively, nurses and other health-care professionals can encourage and perhaps counsel family and friends to address spiritual issues with the patient if needed.

This review suffers from some limitations. Firstly, the literature search was restricted to English and Dutch language publications. Therefore, important publications and unpublished data may have been missed. Secondly, the majority of the studies in this review were conducted in the USA (31 of 38). According to the World Factbook of the USA Central Intelligence Agency 81% of Americans adhere to one of the three major religions (Christianity, Judaism, Islam), which may differ considerably from other countries. For example, of the Dutch population only 57% adheres to some form of religion. In consequence, the spiritual beliefs, experiences, and needs of Americans may be quite different from those of the Dutch, which may influence the relationship between spirituality and well-being. On the other hand, the studies that were conducted in non-USA countries reported similar findings as the American studies.

In summary, in spite of the many studies that report a positive relationship between spirituality and well-being, uncertainty remains about the nature of this relationship, because most studies had a cross-sectional design and there was content overlap between the spirituality and well-being questionnaires. We therefore recommend the use of a longitudinal design and spirituality and well-being questionnaires that do not overlap in content. However, patients do report spiritual needs that should be addressed in health care. The best way of doing so seems to be by counselling family and friends in addressing spiritual needs with the patient.

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3

Existential well–being: Spirituality or well–being?[2]

2 This chapter is under review for publication in a slightly different form as: Visser, A., Garssen, B., & Vingerhoets, A.J.J.M. (under review). Existential well-being: Spirituality or well-being? *Journal of Nervous and Mental Disease*.

Abstract

Measures of spirituality often contain the dimension Existential Well-being (EWB). However, EWB has been found to overlap with well-being. Using the Spiritual Attitude and Involvement List we have further investigated the overlap between aspects of spirituality and well-being among cancer patients, by determining (a) the divergent validity of the subscales of the Spiritual Attitude and Involvement List compared to a well-being questionnaire, (b) the differences in the pattern of change between the measures over a one year period, and (c) the differences in their associations to pain, fatigue, and the occurrence of negative life events. Our findings suggest that a belief that one is able to cope with difficulties of life belongs to the realm of well-being, instead of spirituality. These results can bring researchers a step further toward constructing 'pure' spirituality and well-being measures, which will allow them to investigate the (causal) relationship between these constructs.

Introduction

> [Instruments used to measure spirituality] are heavily contaminated with questions assessing positive character traits or mental health: optimism, forgiveness, gratitude, meaning and purpose in life, peacefulness, harmony, and general well-being. Spirituality, measured by indicators of good mental health, is found to be correlated with good mental health. … Such associations are meaningless and tautological. Either spirituality should be defined and measured in traditional terms as a unique, uncontaminated construct, or it should be eliminated from use in academic research. (Koenig, 2008, p. 349)

The concern voiced by Koenig (2008) seems to stem from a difference in assumptions between the researchers who construct spirituality questionnaires and those who use them to investigate the relationship between spirituality and mental health. The observation that spirituality scales often contain questions that reflect positive mental health indicates that the scale constructors assume that spirituality and mental health are part of the same domain of psychological functioning (MacDonald, 2011). For example, Kapuscinsky and Masters (2010) found in their critical review of 24 spirituality questionnaires that 95% included an emotional component, and 41% of the 22 definitions provided with these scales made mention of feelings and perceptions such as love, closeness, and reverence. In the general population spirituality is also often defined in terms of mental health and positive dimensions of life, such as love, harmony, self-understanding, and acceptance (Berghuijs, Pieper, & Bakker, 2013; Hvidt, Ausker, & la Cour, 2012; Mattis, 2000). However, many researchers try to determine whether spirituality causes, or at least predicts, mental health. Such a hypothesis reflects an underlying assumption that spirituality and mental health are two distinct concepts or domains that are independent of each other, though they may be (causally) related (MacDonald, 2011). Unfortunately, this hypothesis cannot be tested if the available spirituality scales were made under the assumption that spirituality and mental health are (part of) the same concept.

In order to establish with more certainty whether spirituality and mental health belong to the same domain or to different domains that are causally related, we need to construct spirituality scales that do not contain items that measure mental health. This means that we need to determine which aspects of our current conceptualizations of spirituality are distinguishable from mental health and which belong to the same domain as mental health.

A recent study by Migdal and MacDonald (2013) has already made a step in the right direction. They investigated the overlap between a 30-item version of the Expressions of Spirituality Inventory (ESI; MacDonald, 1997, 2000) and several measures of well-being. The ESI contains five subscales that were constructed on the basis of a factor analytical synthesis of 20 existing measures of spirituality and related constructs. Therefore, this measure might be considered representative of a large proportion of the conceptualizations of spirituality. It

was found that only the subscale Existential Well-being (EWB) showed overlap with aspects of well-being or mental health: self-esteem, happiness, overall wellness, life satisfaction, and various dimensions of psychological well-being as defined by Ryff (1989). Together, these measures explained 54% of the variance in EWB (Migdal & MacDonald, 2013). Earlier, MacDonald (2000) found that EWB is strongly negatively correlated with neuroticism (r = -.66), which also suggests some degree of overlap between EWB and a low degree of negative emotionality.

EWB as defined by MacDonald (2000) "pertains to spirituality as expressed through a sense of meaning and purpose for existence, and a perception of self as being competent and able to cope with the difficulties of life and limitations of human existence." (p. 187). EWB stems from the concept of spiritual well-being, which reflects the extent to which people live in harmony in relationship with themselves, others, nature, and the transcendent (National Interfaith Coalition on Aging, 1975). In questionnaires that measure spiritual well-being, EWB is operationalized in terms of an experience of meaning, purpose, value, and satisfaction in life (Edmondson, Park, Blank, Fenster, & Mills, 2008; Ledbetter et al., 1991; Mazzotti, Mazzuca, Sebastiani, Scoppola, & Marchetti, 2011; Paloutzian & Ellison, 1982).

In our own research into the relationship between spirituality and well-being among cancer patients we assume that spirituality and well-being are two separate domains. We use a questionnaire – the Spiritual Attitude and Involvement List (SAIL) – that is based on the following definition of spirituality: "[spirituality is] one's striving for and experience of connectedness with the essence of life" (p. 142), which can be found in relationship with oneself, others, nature, and/or the transcendent (de Jager Meezenbroek et al., 2012). Although care has been taken during scale construction to not directly refer to positive feelings and states, such as love, peace, harmony, or satisfaction with life, the questionnaire does assess several aspects that resemble EWB, such as the experience of meaning and purpose in life, the experience of trust in one's ability to cope with difficulties in life, and the experience of acceptance that some things are outside of one's control and that life is not always without tragedy. Therefore, in the current study we examine the overlap between the measures of spirituality and of well-being that we use in our research among cancer patients.

The purpose of the current study is not only to ensure that we ourselves do not reach tautological conclusions, but also to provide more information on the construct validity of the SAIL, and to provide guidance to other researchers on which aspects of spirituality are conceptually related to well-being. With this knowledge spirituality questionnaires can be devised that measure spirituality as a unique, uncontaminated construct that can be used to uncover the nature of the relationship between spirituality and well-being or mental health.

Because we have only one measure available for each concept, we apply triangulation of statistical tests to increase the credibility of the findings. This triangulation consists of the following: First, we perform a principle component analysis to investigate the divergent validity of the SAIL compared to the well-being questionnaire. Second, we examine the pattern of change of the two constructs over two periods of six months. Third,

we determine the strength of the associations between changes in spirituality and well-being during two periods of six months with changes in factors that are known to influence well-being: physical complaints (pain and fatigue) and the occurrence of negative life events.

When examining the pattern of change, we investigate whether spirituality and well-being change to the same extent and in the same direction. Several studies have indicated that the level of spirituality of an individual may be rather stable (Bradshaw & Ellison, 2008; Saucier & Skrzypinska, 2006), whereas the level of well-being may be expected to fluctuate over time. In addition, we would expect the two constructs to not necessarily change in the same direction, if they are different from each other. We would also expect changes in well-being to be more strongly associated with changes in physical complaints and with the occurrence of negative life events than would the changes in any aspect of spirituality, if spirituality and well-being do not overlap.

Methods

Participants

In the context of a larger study on the relationship between spirituality and well-being among cancer patients, approximately 1489 persons with cancer were invited to participate in the study and to fill out a set of questionnaires at three time-points over the course of a year. Participants were recruited from four hospitals and two radiotherapy institutions in the Netherlands, by a member of the medical staff. Patients were eligible for participation if they met the following criteria: They were 18 years of age or older, they were Dutch-speaking, they were treated for cancer with a curative intent, their primary treatment for cancer was surgery or radiotherapy, their treatment had not started more than two months previously, they did not have a psychiatric disorder, they did not have a brain tumor.

During recruitment we had attempted to limit a selection bias based on spiritual involvement by urging the members of the medical staff to approach all patients, and certainly not only those patients with an open-mind with respect to spirituality. Also, the information sheet for eligible patients included the following sentences: “Everyone who is treated for cancer is cordially invited to participate in this study. Even if you consider spirituality to be a vague concept or if you feel that’s ‘not my sort of thing’ you can contribute to the study”. This seemed to have been effective, as the proportions of Protestants, Roman Catholics, adherers to another philosophy of life, and persons who did not adhere to a denomination in the study sample were comparable to those in the general Dutch population (Statistics Netherlands, 2010).

About one-third of the patients who were approached for participation in the study provided written informed consent and filled out the first questionnaire (T1; N = 460), either by paper-and-pencil or on the internet. Participants received a gift certificate of €7.50 with their first questionnaire. The main reasons for declining participation were that the person was not willing to participate in research, felt very distressed, or was not interested in spirituality. After six months the participants were asked to fill out the questionnaires a second time

(T2), to which 408 persons (response rate = 89%) responded. After another six months, the final assessment took place (T3). This third questionnaire was filled out by 383 participants (retention rate = 83%). The main reasons for attrition during the study were death (N = 7), non-response (N = 16) and no longer feeling motivated to fill in the questionnaires (N = 7). In addition, two participants had developed psychological problems that prevented them from completing the study and two participants became too ill. Socio-demographic and medical characteristics of the sample are presented in Table 3.1.

Table 3.1 Socio–demographic and medical characteristics of the study sample compared to the Dutch population

	Study sample (N = 460)	Normative data
Median age in years (range)	59 (24 – 84)	60-74 (0 – 75+) [a]
Gender (%)		
Male	121 (27)	52 [b]
Female	323 (73)	48
Educational level (%)		
Low	83 (19)	
Middle	181 (41)	
High	177 (40)	
Denomination (%)		
Protestant	119 (27)	18 [c]
(Roman) Catholic	111 (25)	28
Other	45 (3.4)	10
None	168 (38)	44
Considers oneself religious (%)		
Yes	233 (53)	
No	187 (42)	
Doubt	23 (5)	
Considers oneself spiritual (%)		
Yes	220 (50)	
No	186 (42)	
Doubt	35 (8)	

(Table 3.1 continued)

Type of cancer (%)		
Breast	275 (62)	14 [d]
Prostate	52 (12)	11
Digestive system	80 (18)	22
Other	33 (8)	53
Mean scores on the SAIL (SD)		
Meaningfulness	4.42 (.71)	
Trust	4.42 (.64)	
Acceptance	4.51 (.73)	
Caring for Others	4.69 (.63)	
Connectedness with Nature	4.73 (.93)	
Transcendent Experiences	2.44 (1.07)	
Spiritual Activities	3.00 (1.27)	
Mean score on the JiL (SD)	57 (6.40)	

[a] Median age of all new cancer patients with an invasive tumor in the Netherlands in 2009 and 2010, Comprehensive Cancer Centre (2011), www.cijfersoverkanker.nl

[b] Percentage of all new cancer patients with an invasive tumor in the Netherlands in 2009 and 2010, Comprehensive Cancer Centre (2011), www.cijfersoverkanker.nl

[c] Percentages of Dutch population in 2009, Statistics Netherlands (15-10-2010), http://statline.cbs.nl/StatWeb/publication/?DM=SLNL&PA=37944&D1=a&D2=29-40&HDR=T&STB=G1&VW=T

[d] Percentage of all new cancer patients with an invasive tumor in the Netherlands in 2009 and 2010, Comprehensive Cancer Centre (2011), www.cijfersoverkanker.nl

SAIL = Spiritual Attitude and Involvement List, JiL = Health and Disease Inventories subscale Joy in Life

Questionnaires

Spirituality The Spiritual Attitude and Involvement List (SAIL; de Jager Meezenbroek et al., 2012) was used to assess spirituality. This questionnaire was based on discussions with 30 experts from the Netherlands (psychological researchers, psychotherapists, theologians, pastoral workers, and medical doctors) about what constitutes spirituality; focus groups with six other experts and eight lay persons on the suitability, comprehensibility, ambiguity, and redundancy of the scale items; and psychometric testing among 950 students, 466 healthy persons, and 219 cancer patients. The SAIL consists of seven distinctive subscales that represent many of the experiential and attitudinal aspects frequently considered to be part of spirituality (Chiu, Emblen, van Hofwegen, Sawatzky, & Meyerhoff, 2004; Cohen, Holley, Wengel, & Katzman, 2012; Tanyi, 2002).

The items of the subscales Meaningfulness, Trust, Acceptance, Caring for Others, and Connectedness with Nature are rated on a 6-point scale ranging from 1 “not at all” to

6 “to a very high degree”. The subscales Transcendent Experiences and Spiritual Activities are rated from 1 “never” to 6 “very often”. For all subscales mean scores are calculated, with higher scores representing more spiritual involvement. The reliability (internal consistency and test-retest reliability) and validity (factor-analytic validity and convergent and divergent validity) have proven sufficient (de Jager Meezenbroek et al., 2012). In the current sample the internal consistencies of the subscales ranged from Cronbach α = .75 to .89. The six month test-retest reliabilities ranged from r = .64 to .72, and the twelve month test-retest reliability ranged from r = .66 to .87.

The SAIL consists of the following subscales: Meaningfulness (3 items), which measures the person’s sense of meaning and purpose in life. For example, “I experience the things I do as meaningful”; Trust (4 items), which measures whether the person approaches life and its events with a feeling of confidence or trust. For example, “In difficult times, I maintain my inner peace”; Acceptance (4 items), which measures whether the person can accept life as it unfolds. For example, “I am aware that each life has its own tragedy”; Caring for Others (4 items), which assesses the person’s need to be available to others. For example, “I try to make a meaningful contribution to society”; Connectedness with Nature (2 items), which measures the person’s experience of nature. For example, “The beauty of nature moves me”; Transcendent Experiences (5 items), which assesses whether the person has ever had such an experience. For example, “I have had experiences in which all things seemed to be part of a greater whole”; Spiritual Activities (4 items), which contains three items that assess the person’s involvement in spiritual activities [e.g., “I talk about spiritual themes with others (themes such as the meaning in life, death or religion)”] and one item that asks whether the person feels that there is a God or higher power in his/her life that gives him/her guidance.

Well-being In order to measure well-being in a broad, but brief manner, the Joy-in-Life subscale of the Health and Disease Inventories was used (HDI; de Bruin & van Dijk, 1996). The HDI is a Dutch questionnaire designed to assess adjustment to cancer. The Joy-in-Life scale assesses well-being as the experience of positive affect (for example, “I enjoy the things I do”, “I feel lovingly cared for by others”, and “I feel safe”) and of vitality (for example, “I feel I do a lot during the day”). This scale previously showed reliability of α = .82 in a sample of 460 cancer patients. Its convergent and divergent validity were found satisfactory; the Joy-in-Life scale was negatively related with the distress scales of the Profile of Moods States (POMS; Wald & Mellenbergh, 1990) and the Rotterdam Symptom Checklist (de Haes, van Knippenberg, & Neijt, 1990), but positively with the Vigour subscale of the POMS. In the current sample, the internal consistency of this HDI subscale ranged from α = .91 to .92 across the three assessments.

Fatigue Fatigue was measured with the four-item version of the Checklist Individual Strength (CIS; Alberts, Smets, Vercoulen, Garssen, & Bleijenberg, 1997). Norm data on this scale are available for several healthy and patient populations, including cancer patients (Alberts et al., 1997). The shortened version is closely related to the often used, valid and reliable longer version of the CIS (Vercoulen, Alberts, & Bleijenberg, 1999). Participants were

asked to rate whether they felt tired, were easily tired, felt well, and felt physically exhausted on a 7-point scale ranging from 1 "Yes, that is true" to 7 "No, that is not true". The item "I feel well" was reverse scored. The internal consistency of the scale was α = .89 to .90 in the current sample.

Pain The symptom scale on pain from the Dutch translation of the European Organization for Research and Treatment of Cancer, Quality of Life Questionnaire-C30, version 1 (EORTC-QLQ-C30; Aaronson et al., 1993) was used to assess the degree of pain of the participants. Participants were asked to rate on a four-point scale, ranging from 1 "not at all" to 4 "very much", how much pain they had experienced during the past two weeks and whether this pain had limited them in their daily activities. In the current study we used the average score of the two items (Fayers, Aaronson, & Bjordal, 1999). Among the cancer patients in the present study the internal consistencies of the scale ranged from Cronbach α = .89 to .91 across the three assessments.

Negative life events The number of negative life events were measured only at T2 and T3. Participants were asked to indicate how often they had experienced a negative life event that had a great impact on their lives during the past 6 months - for example illness other than cancer, a death, relationship problems, or financial problems (none, 1 or 2 times, 3 or 4 times, or 5 times or more, respectively).

Statistical analyses

Preliminary analyses

Missing value analysis on the SAIL and Joy-in-Life scale (JiL) indicated that up to six participants (1.1%) had not completed up to four items per scale. Little's MCAR test indicated that at T1 scores on the JiL and on the SAIL subscales Acceptance, Caring for Others, and Transcendent Experiences were not missing completely at random. On these scales most missing data came from one participant whose data was, therefore, removed from the dataset. Most of the remaining missing data was centered on one item of the SAIL subscale Transcendent Experiences, which suggests that this was not missing at random. Therefore, these scores were not imputed. Finally, it was assumed that the remaining missing scores were missing at random if a participant had completed more than 75% of the items of the scale. In these cases, the scores were replaced by two-way imputation (Bernaards & Sijtsma, 2000; van Ginkel & van der Ark, 2005).

To investigate whether attrition to the study was selective on spirituality, well-being, or physical symptoms, the participants who had dropped out of the study at T2 or T3 (N = 61) were compared with those who had completed all three assessments (N = 382) on spirituality, well-being, pain, and fatigue at T1. Independent samples t-tests indicated that the drop-outs experienced significantly more fatigue (M = 16.32, SD = 6.96 and M = 13.30, SD = 6.74, respectively; $t(441) = -3.21$, $p = .001$) and pain (M = 2.24, SD = 0.85 and M = 1.78, SD = 0.83, respectively; $t(442) = -3.99$, $p < .001$) than the stay-ins at T1. However, the two groups did not

differ on spirituality and well-being, making any bias in the results due to selective attrition less likely.

Spirituality versus well–being

We have applied several different types of analyses to investigate the similarities and differences between spirituality and well-being. Non-parametric tests were applied in all instances, because the scores on many of the variables did not follow a normal distribution. All analyses were performed with IBM SPSS statistics version 19 (IBM Company, 2010).

First, we investigated the divergent validity of the SAIL compared to the JiL by including the items of both questionnaires as assessed at T1 in a Principal Component Analysis. Varimax rotation with Kaiser normalization was used to enhance the interpretation of the results.

Second, we examined whether spirituality and well-being developed differently over the three measurement points. We tested the hypothesis that well-being changed more than spirituality or that well-being changed in a different direction than spirituality. Therefore, we calculated two scores for all variables involved: change from T1 to T2 and change from T2 to T3. Change over the entire year was not investigated, because curative cancer treatment is usually completed about six months after diagnosis and after this time the patient goes into a phase that is more focused on rehabilitation instead of survival. Thus, the two time periods may be very different psychologically and emotionally, and much information would be lost if they were to be combined into one change score. The scores on well-being were transformed so that these change scores would have the same possible range as the change scores in spirituality.

We used the binomial test and assigned a 1 to all cases for which the change on a subscale of the SAIL was in a different direction from the change on the JiL or - if they changed in the same direction - the change on the JiL was larger than the change on the subscale of the SAIL. In all other cases we assigned a 0. The null-hypothesis of the binomial test is that the proportions of 1s and 0s are equal.

For several reasons we have chosen not to apply the more standard techniques for the type of data available, such as repeated-measures analysis of variance (rmANOVA), a general change or stability coefficient such as r or Cohen's d, or latent growth modelling (LGM). Most of the data was skewed, so estimations of the mean change on each variable would be biased. In addition, these techniques do not (easily) allow for a direct comparison of differences in change between two variables, whereas we wanted to provide a statistical test of the difference in change between the aspects of spirituality and well-being. Finally, we wanted to be able to take into account differences in both the size and the direction of change on an individual level, which is not possible with rmANOVA or a stability/change coefficient.

Third, we tested whether the changes in spirituality and well-being between T1 and T2 and between T2 and T3 were related differently to external factors that are known

to predict changes in mood. For this purpose, Spearman rank-order correlations were calculated between, on the one hand, the raw change scores of well-being and the aspects of spirituality, and, on the other hand, the number of negative life events and changes in pain and in fatigue. The function compCorr, available in the package maigesPack of R for statistical computing (R Developmental Core Team, 2011), was used to test the difference between the two correlation coefficients.

Results

Divergent validity

The Principal Component Analysis (PCA) resulted in eight components with eigenvalues of 1 or higher. Varimax rotation converged after 12 iterations. All items with component loadings ≥ .30 were considered to belong to a component. If items belonged to more than one component, the item was included in the component with the highest loading or the item was grouped within the component that was most similar in content. The results are displayed in Table 3.2.

Most of the items of the JiL were included in component 1, reflecting a sense of vitality and pleasure. The other items of the JiL were included in component 4, together with three of the four items of the SAIL subscale Trust and one item of the SAIL subscale Meaningfulness. This component seems to reflect feelings of peace, confidence, and safety. The remaining item of the SAIL subscale Trust was included in component 5, together with the items of the SAIL subscale Acceptance, reflecting an attitude of acceptance toward (negative) events in life. The remaining items of the SAIL subscale Meaningfulness were included in component 3, together with the items of the SAIL subscale Caring for Others, reflecting feelings of compassion, a sense of duty to be meaningful to others, and an experience of meaning and purpose in one's own life. The items of the SAIL subscales Connectedness with Nature, Transcendent Experiences, and Spiritual Activities were included in components 7, 6, and 2, respectively.

Table 3.2 Results of a Principal Component Analysis with Varimax rotation of the items of the SAIL and the JiL

	Component							
	1	2	3	4	5	6	7	8
JiL 1	**.67**							
JiL 2	**.66**							
JiL 3	**.73**							
JiL 4	**.67**							
JiL 5	**.72**							
JiL 6	**.65**							.40
JiL 7	**.70**							
JiL 8	**.74**			.36				
JiL 9	**.78**							
SAIL 19 (E)		**.76**						
SAIL 20 (E)		**.79**						
SAIL 21 (E)		**.82**						
SAIL 23 (E)		**.75**						
SAIL 25 (E)		**.73**						
SAIL 2 (C)			**.76**					
SAIL 7 (C)			**.68**					.34
SAIL 12 (M)			**.55**					
SAIL 16 (C)			**.76**					
SAIL 17 (M)			**.55**					
SAIL 18 (C)			**.83**					
SAIL 1 (T)				**.56**				
SAIL 3 (T)				**.62**				
SAIL 4 (M)			.34	**.57**				
SAIL 9 (T)	.37			**.45**	.35			
JiL 10	.26			**.26**				.55
JiL 11	.43			**.61**				
JiL 12	.43			**.59**				
JiL 13	.35			**.58**				.41
SAIL 6 (A)					**.67**			
SAIL 8 (A)					**.80**			
SAIL 11 (A)			.33		**.52**			
SAIL 13 (T)				.32	**.58**			
SAIL 15 (A)					**.62**			
SAIL 10 (S)						**.70**		
SAIL 22 (S)		.51				**.54**		

(Table 3.2 continued)

SAIL 24 (S)		.42				**.66**		
SAIL 26 (S)						**.79**		
SAIL 5 (N)							**.82**	
SAIL 14 (N)							**.84**	
Rotation sums of squared loadings	5.48	3.91	3.74	3.13	2.87	2.53	1.69	1.24
% of variance explained	14.05	10.02	9.60	8.04	7.36	6.49	4.33	3.17

Note Only component loadings > .25 are shown.

M = Meaningfulness, T = Trust, A = Acceptance, C = Caring for Others, N = Connectedness with Nature, E = Transcendent Experiences, S = Spiritual Activities.

Spearman rank-order correlations were calculated between the original scales to confirm the findings of the PCA (see Table 3.3). The high correlations between the JiL total score, the SAIL subscale Meaningfulness, and the SAIL subscale Trust confirm the overlap found in the PCA. The overlap between the SAIL subscales Meaningfulness and Caring for Others is also confirmed by the correlation coefficients.

Table 3.3 Spearman rank–order correlations between the Joy–in–Life scale (JiL) and the subscales of the Spiritual Attitude and Involvement List (SAIL)

	JiL	SAIL-M	SAIL-T	SAIL-A	SAIL-C	SAIL-N	SAIL-E
SAIL-M	.51						
SAIL-T	.55	.58					
SAIL-A	.29	.49	.48				
SAIL-C	.25	.58	.33	.37			
SAIL-N	.18	.36	.23	.40	.37		
SAIL-E	.01	.25	.19	.27	.27	.28	
SAIL-S	.06	.31	.15	.40	.33	.28	.58

M = Meaningfulness, T = Trust, A = Acceptance, C = Caring for Others,
N = Connectedness with Nature, E = Transcendent Experiences, S = Spiritual Activities.

Differences in change over time

The results of the binomial tests are presented in Table 3.4. For all comparisons the proportion of 1s was significantly larger than would be expected under a binomial distribution.

Table 3.4 Binomial test of the extent and direction of change in well–being compared to spirituality

	Range of absolute change	Observed proportions		p
		1	0	
	T1 – T2			
Well-being [a]	0 – 2.38			
Meaningfulness	0 – 2.33	.66	.34	< .001
Trust	0 – 3.75	.70	.30	< .001
Acceptance	0 – 2.50	.68	.32	< .001
Caring for Others	0 – 2.25	.72	.28	< .001
Connectedness with Nature	0 – 2.00	.71	.29	< .001
Transcendent Experiences	0 – 3.20	.68	.32	< .001
Spiritual Activities	0 – 2.75	.69	.31	< .001
	T2 – T3			
Well-being [a]	0 – 1.92			
Meaningfulness	0 – 1.67	.69	.31	< .001
Trust	0 – 3.50	.70	.30	< .001
Acceptance	0 – 2.00	.70	.30	< .001
Caring for Others	0 – 2.00	.73	.27	< .001
Connectedness with Nature	0 – 2.00	.72	.28	< .001
Transcendent Experiences	0 – 3.40	.67	.33	< .001
Spiritual Activities	0 – 1.75	.71	.29	< .001

Note 1 = well-being changes more than spirituality OR well-being and spirituality change in different directions.
0 = well-being changes less than spirituality OR well-being and spirituality change equally.
[a] Joy-in-Life total score / 13

Association with pain, fatigue and life events

To prevent artificial inflation of the correlation coefficient, we removed item 9 from the JiL ("I feel fit") when calculating the correlation between the JiL and fatigue.

Changes in fatigue and pain were related more strongly to changes in well-being than to changes in spirituality, both in the interval from T1 to T2 and in the interval from T2 to T3. However, the number of negative life events experienced between T1 and T2 and

between T2 and T3 was related equally weakly to the changes in spirituality as to the changes in well-being (see Table 3.5).

Discussion

We investigated which aspects of spirituality may be considered to be truly unique for this construct and which might need to be viewed as belonging to the domain of mental health or well-being. Based on our findings, we conclude that the experiences of trust in one's ability to cope with difficulties in life resembles well-being instead of spirituality. These experiences are measured in the subscale Trust of the Spiritual Attitude and Involvement List (SAIL; de Jager Meezenbroek et al., 2012). In a Principal Component Analysis (PCA) three of the four Trust items and one of the four Meaningfulness items shared a component with four items of the well-being measure we used, the Joy-in-Life scale (JiL; de Bruin & van Dijk, 1996). These items all reflected feelings of peace, confidence, and safety. Other studies have also indicated that the SAIL subscale Trust has unsatisfactory concurrent validity (de Jager Meezenbroek et al., 2012; Garssen, Uwland & Visser, in preparation). Nevertheless, Trust was less strongly correlated with fatigue and pain than was well-being, and the binomial test indicated that it occurred more often that the change in well-being was larger than the change in Trust or

Table 3.5 Spearman rank–order correlations of the change in spirituality and well–being with the change in fatigue, pain, and the number of negative life events

	T1 – T2			T2 – T3		
	Fatigue	Pain	Negative life events	Fatigue	Pain	Negative life events
Well-being	-.28	-.17	-.02	-.35	-.18	-.09
Meaningfulness	-.02***	.06***	.02	-.08***	.06***	.01
Trust	-.10**	.04**	-.08	-.17**	-.10	-.07
Acceptance	-.04***	.06***	-.06	-.09***	-.02**	.01
Caring for Others	.01***	-.05*	-.03	-.04***	-.01**	.12**
Connectedness with Nature	-.04***	.10***	-.002	-.06***	.06***	.01
Transcendent Experiences	.10***	.08***	-.01	.02***	.02**	-.04
Spiritual Activities	.05***	.04**	-.09	.03***	.04**	-.01

* $p \leq .05$ ** $p \leq .01$ *** $p \leq .001$ for the test of the difference between the correlation coefficients of well-being with fatigue, pain, or negative life events and the correlation coefficients of the aspects of spirituality with fatigue, pain, or negative life events.

that they changed in a different direction. These seemingly contradictory findings may be explained by the finding that Trust did no overlap with the items of the JiL that measured the experience of vitality and pleasure, which may be less stable and more strongly affected by physical symptoms.

The results further suggest that Meaningfulness, Acceptance, Caring for Others, Connectedness with Nature, Transcendent Experiences, and Spiritual Activities are not indicative of well-being. These subscales showed divergent validity compared to the JiL, did not change in the same direction or at the same rate as well-being, and were related less strongly to fatigue and pain than was well-being.

An important finding is that the experience of meaning and purpose in life seems to be more indicative of spirituality than of well-being. Instead, the PCA indicated that Meaningfulness may be more closely related to Caring for Others, as the items from these SAIL subscales loaded on the same component and their total scores are highly correlated. It does not seem unlikely that feelings of compassion and of duty toward others provide a person with a sense of meaning and purpose in life.

The results from our study partially confirm the finding by Migdal and MacDonald (2013) among undergraduate students that the subscale Existential Well-Being (EWB) of the Expressions of Spirituality Inventory (ESI; MacDonald, 1997) seems to belong to the domain of well-being, instead of spirituality. This ESI subscale measures a sense of meaning and purpose for existence and of competence and confidence in one's ability to cope (MacDonald, 2000). Within our study, the latter is reflected within the SAIL subscale Trust, whereas the SAIL subscale Meaningfulness mirrors the EWB experiences of meaning and purpose in life. As shown, these two subscales are differently related to well-being, which also suggests that the concept of EWB contains components that are related, but belong to different domains of human experience. Further research is needed to fully understand where spirituality and well-being diverge.

Several limitations to the current study need to be addressed. First, we have used only one measure of spirituality and of well-being to investigate the conceptual difference between the two, so the results may be specific to these operationalizations of the concepts. On the other hand, the SAIL was based on extensive discussions between experts on spirituality in the Netherlands and the subscales correspond to what are regarded important aspects of spirituality by authors in the field (Chiu, 2004; Cohen, et al., 2012; Tanyi, 2002). Our measure of well-being also covers a range of aspects that are considered to be important about the concept of well-being. Nevertheless, future studies with the primary goal to investigate the conceptual difference between spirituality and well-being should utilize several measures of spirituality and of well-being, to understand more fully how these broad concepts relate to each other and where the domain of the one begins and that of the other ends.

Second, only a small proportion of the sample had substantially changed in their level of well-being over the course of the study, which may lead one to question the accuracy of our initial assumption; that we could show that spirituality and well-being are two different

construct because spirituality is expected to be more stable than well-being. Other studies that have used different scales to investigate the development of well-being among various groups of cancer patients have also demonstrated that the level of psychosocial adjustment or well-being is quite stable among the majority of patients (Helgeson, Snyder, & Seltman, 2004.; Henselmans, Helgeson, Seltman, & de Vries, 2010; Nosarti, Roberts, Crayford, McKenzy, & David, 2002; Vos, 2008). So well-being, like spirituality, might be a trait instead of a state. Nevertheless, our study suggests that these two traits are distinguishable from each other.

Now that we have gained a further understanding of which aspects of spirituality scales might be unique to this construct, we can begin to take steps toward investigating the true nature of the relationship between spirituality and mental health: Are they part of the same domain or are they causally related? Comparative studies on psychological interventions with and without a spiritual connotation or studies on the experiences of novices within a spiritual tradition may provide some clues toward answering these questions. For those researchers who want to undertake such efforts, we paraphrase the advice by MacDonald (2011): (a) utilize empirically validated, multidimensional models and measures wherever possible, (b) make use of existing theories and measures, so the area of study is both legitimized and developed further, (c) use multiple, complementary methods, such as quantitative self-report measures, registration of observable and quantifiable behavior, and qualitative methods, (d) take into account both the positive and the negative influences of spirituality on human functioning.

To conclude, it seems that spirituality questionnaires should not include an aspect of trust or self-efficacy - a sense that one is able to cope with difficulties of life -, because this is not unique to spirituality and, instead, seems to belong to the realm of mental health. Other aspects of spirituality seem to be distinct from well-being, such as a sense of meaning and purpose in life, acceptance, caring for others, connectedness with nature, transcendent experiences, and spiritual activities. The results from the present study speak for the construct validity of the Spiritual Attitude and Involvement List and enable researchers to construct spirituality scales that do not show overlap with mental health. Such scales will allow them to investigate the causal relationship between spirituality and well-being without arriving at meaningless and tautological conclusions.

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4

Examining whether spirituality predicts subjective well–being: How to avoid tautology[3]

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Abstract

Spirituality may help people to maintain a high level of well-being despite adversity, but several studies that claim to support this statement have used spirituality scales and outcome measures that have overlapping content. This practice seems to be widespread: In an exploratory survey of eight well-cited journals we found that 26 of 58 studies used a spirituality scale that contains 25% or more items that refer to well-being, to examine whether spirituality predicts well-being or distress. These spirituality questionnaires would be more appropriate for use as indicators of the domain of quality of life called spiritual well-being. We urge researchers to only use spirituality questionnaires of which less than 25% of the items refer to emotional well-being – such as the SWB Questionnaire or the Spiritual Attitude and Involvement List - when investigating the causal relationship between spirituality and emotional well-being.

Introduction

Spirituality is an important part of the lives of many people. It involves beliefs about the meaning of events and about what is of value in life. Spirituality remains difficult to precisely define, but there is general agreement that it refers to a connection with a larger reality that gives one's life meaning, experienced through a religious tradition or, increasingly in secular Western culture, through meditation, nature, or art (Peteet & Balboni, 2013). Most definitions emphasize the overlap between spirituality and religion. We define spirituality as "one's striving for and experience of connection with the essence of life" (de Jager Meezenbroek et al., 2012a, p. 142), which encompasses three main dimensions: connectedness with oneself, connectedness with others and nature, and connectedness with the transcendent. The term 'transcendence' may, but does not necessarily, represent God. This definition concurs with literature on non-theistic spirituality. For example, the National Interfaith Coalition on Aging (National Interfaith Coalition on Aging, 1975) described spirituality as the affirmation of life in a relationship with the self, community, environment and God; a working definition that emerged from several meetings with representatives from various religions. Several reviews have also asserted that connectedness is a predominant theme in definitions of spirituality (Chiu, Emblen, van Hofwegen, Sawatzky, & Meyerhoff, 2004; Dyson, Cobb, & Forman, 1997).

Spirituality is related with higher well-being, as has been shown in several reviews and meta-analyses (Ano & Vasconcelles, 2005; George, Larson, Koenig, & McCullough, 2000; Hackney & Sanders, 2003; Sawatzky, Ratner, & Chiu, 2005; Smith, McCullough, & Poll, 2003; Visser, Garssen, & Vingerhoets, 2010; Yonker, Schnabelrauch, & Dehaan, 2012). The findings of these reviews and meta-analyses may give the impression that it has been proven beyond doubt that spirituality contributes to a sense of well-being. However, most of the studies included in these reviews and meta-analyses have used a cross-sectional design. Longitudinal studies may provide indications for the existence of causal relationships, but so far they have shown mixed findings (Visser et al., 2010).

Another problem in this area of research is that several studies have used spiritual well-being (SWB) scales to test the effect of spirituality on well-being. This problem is the focus of the present paper. According to Gomez and Fisher (2003) SWB can be defined in terms of a state of being that reflects positive feelings, behaviors, and cognitions of relationships with oneself, others, the transcendent, and nature. This state of being provides the individual with a sense of identity, wholeness, satisfaction, joy, contentment, beauty, love, respect, positive attitudes, inner peace and harmony, and purpose and direction in life. So on a conceptual level there is considerable overlap between SWB and emotional well-being (EWB). This makes SWB scales suitable for use as outcome variables. However, if an SWB scale is used to asses a person's level of spirituality in order to predict his/her level of EWB from this, then the content overlap between the questionnaires will artificially increase the strength of the association.

We do not dispute that SWB is a concept that has theoretical meaning within the well-being framework. There are also numerous situations in which it is important to determine

whether a person experiences peace, comfort, strength, satisfaction, etc. within or from their spirituality. For example, when a mental health professional wants to determine whether it would be appropriate to include a person's spirituality in a psychological intervention, or when one tries to determine whether a person experiences religious struggle (which would be the opposite of SWB). However, when examining whether a causal relationship exists between two concepts it is of the utmost methodological importance that the measurement instruments that are used to assess the concepts are unique. Otherwise, it is impossible to determine the effect of, in this case, spirituality on emotional well-being, because the conceptual overlap would cause inflation in the strength of the relationship.

Our concern has been expressed before (Garssen, Visser, & de Jager Meezenbroek, 2012a; Garssen, Visser, & de Jager Meezenbroek, 2012b; Kapuscinski & Masters, 2010; Koenig, 2008; Migdal & MacDonald, 2013; Tsuang, Simpson, Koenen, Kremen, & Lyons, 2007; Visser et al., 2010), and most sharply by Koenig, who wrote: "[Spirituality scales] are heavily contaminated with questions assessing positive character traits or mental health: optimism, forgiveness, gratitude, meaning and purpose in life, peacefulness, harmony, and general well-being. Spirituality, measured by indicators of good mental health, is found to be correlated with good mental health. This research has been reported in some of the world's top medical journals. Such associations are meaningless and tautological" (Koenig, 2008, p. 349). However, we are under the impression that, despite Koenig's warning, the practice is still widespread. Therefore, the purpose of this paper is not only to make the readers aware once again that the problem exists, as we have done above, but also to provide guidelines on which spirituality or SWB questionnaires might better not be used as measures of spirituality to determine its effect on EWB.

If the described problem of contamination would be found in a very few publications in relatively unknown journals, one might conclude that the problem does exist but is relatively unimportant. Therefore, we also provide, as an addition, an impression of the proportion of studies that have inappropriately used these scales as a predictor for well-being. We will end the paper with an advice on which questionnaires might be most appropriate to use in research examining the causal relationship between spirituality and EWB.

Spirituality questionnaires that contain emotional well–being items

We included all published SWB scales in our evaluation, supplemented with spirituality scales of which we had found previously that they contained well-being items (de Jager Meezenbroek et al., 2012b). Also included were spirituality questionnaires and questionnaires on religious or spiritual coping that we came upon during our survey of the eight journals (see below).

To determine which items refer to EWB, the three authors of the present paper independently evaluated the questionnaires and determined which items express feelings of well-being or distress. We used the following guideline: If an item of a spirituality or SWB scale could also be an adequate item of an emotional well-being or distress scale, it was

selected as an EWB item. Any disagreements were discussed until consensus was reached. We also selected items that suggest a relationship between spirituality/religion and EWB, such as "Faith contributes to my well-being". These items are labeled as SWB items. In other words, an item is labelled an EWB item if it suggests (asks for) the presence of a positive or negative affect, such as joy, pleasure, anger, and sadness, or a positive mental state, such as peace of mind and strength. If the experience of such an affect or mental state is suggested to occur through the force of a religious entity, such as "I experience joy through my prayers" or "God gives me peace of mind", the item is labeled as an SWB item. Although the experience of purpose in life or meaning in life is close to experiencing positive feelings, we have considered these aspects to be conceptually different from EWB. The overview of the questionnaires evaluated and the items that we considered to be EWB or SWB items are presented in Table 4.1.

Although every emotional or spiritual well-being item in a spirituality scale may contribute to an artificially high relationship with EWB, it would be an overstatement to dismiss every scale that contains a confounding item. Therefore, a scale was deemed acceptable as a unique measure of spirituality, if less than 25% of the items referred to SWB or EWB.

We have based the choice of the cut-off score of 25% on a simulation study. In order to conduct such a simulation one starts with the assumption of no (real) relationship between spirituality and EWB, if unique scales for each concept would have been used. In the simulation, an increasing number of EWB items were introduced in the spirituality scale to see when the correlation coefficient between the total scores of the two scales became significant.[4] The change appeared to occur between an overlap of 20% and 30% of the items. With 25% overlap, the correlation between both simulated scales is $r = .21$, and $p = .02$ with a two-tailed test and $N = 100$ (with 20% overlap $r = 0.17$, $p = .09$; with 30% overlap $r = 0.26$, $p = .01$). The whole procedure was repeated a hundred times to obtain stable correlation coefficients. Correlation coefficients may depend on the number of items in both scales and the range of possible responses to the items of both scales. However, the outcome was not essentially different for a simulated scale of five items and a 5-point response scale (see above), or for a simulated scale of twenty items and a 7-points response scale (20% overlap $r = 0.16$, $p = 0.12$; 25% overlap $r = .20$, $p = .05$; 30% overlap $r = .24$, $p = .02$).

Two SWB scales were identified that include no more than 25% of spiritual well-being or emotional well-being items, and thus might be safely used as predictors of EWB:

- Jarel Spiritual Well-Being Scale (Hungelmann, KenkelRossi, Klaasen, & Stollenwerk, 1996)
- Spiritual Well-Being Questionnaire (SWBQ; Gomez & Fisher, 2003).

4 In fact, the EWB items were drawn from a scale closely associated with the (simulated) EWB scale, such that the highest possible correlation coefficient is r=.80. This was done, because it is unlikely that scales for two similar concepts would have a perfect correlation of r=1.00.

The following eight questionnaires include 25% or more spiritual or emotional well-being items, which makes them inappropriate for use as a predictor of EWB:

- The long 15- or 16-item version (see note [a] below Table 4.1) and the short 6-item version of the Daily Spiritual Experience Scale (DSES; Underwood & Teresi, 2002).
- Functional Assessment of Chronic Illness Therapy - SWB Scale (FACIT-sp; Cella, 1997; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002)
- Religious Coping Activities Scale – subscale Discontent (Pargament et al., 1990)
- Rush Religious/Spiritual Struggle Screening Protocol (Fitchett & Risk, 2009)
- Spiritual Index of Well-Being (SIWB; Daaleman & Frey, 2004)
- Existential and Religious Well-Being Scales of the Spiritual Well-Being Scale (SWBS; Ellison, 1983; Ellison & Smith, 1991)
- World Health Organization Quality Of Life - Spirituality, Religion and Personal Beliefs scale (WHOQOL SRPB; O'Connell, Saxena, & Underwood, 2006).

To illustrate the problem that would arise if one of these eight measuring methods would be used together with an EWB questionnaire, imagine a person who scores high on an item such as "I feel peaceful" and low on such items as "There is a great void in my life at this time" or "I don't enjoy much about life". These are items included in the spirituality questionnaires FACIT-sp, SIWB and SWBS, respectively. This person will probably also score high on items such as "I still enjoy the things I used to" or "I was happy", and low on such items as "I feel miserable and sad", "I feel depressed", or "I feel unhappy". These are items from the distress scales HADS, CES-D, and POMS. Determining a relationship between these measures would only provide information on the subject's EWB, not on the effect of spirituality on EWB. Therefore, it is puzzling to us what would motivate a researcher to study a relationship between concepts using questionnaires that have such similar content.

Table 4.1 Spirituality questionnaires that include well–being items

Name	Total No. of items	No. of (S)WB items	Well-being items	Spiritual well-being items
Daily Spiritual Experience Scale (DSES; Underwood & Teresi, 2002)	16/15 [a]	4 (25/27 %)	I feel deep inner peace or harmony	- During worship, or at other times when connecting with God, I feel joy, which lifts me out of my daily concerns - I find strength in my religion or spirituality - I find comfort in my religion or spirituality
	6	2 (33%)	I find deep inner peace and harmony	I find strength and comfort in my religion

(Table 4.1 continued)

Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being Scale (FACIT-sp; Cella, 1997; Peterman et al., 2002)	12	5 (42%)	- I feel peaceful - I have trouble finding peace of mind - I feel a sense of harmony within myself	- I find comfort in my faith or spiritual beliefs - I find strength in my faith or spiritual beliefs
Jarel Spiritual Well-Being Scale (Jarel; Hungelmann et al., 1996)	21	3 (14%)	- I am pretty well put together - I am satisfied with my life	I belief, I have spiritual well-being
Religious Coping Activities Scale – subscale Discontent (Pargament et al., 1990)	3	2 (66%)		- Felt angry with or distant from God - Felt angry with or distant from members of the church
Rush Religious/Spiritual Struggle Screening Protocol (Fitchett & Risk, 2009)	2 - 3 [b]	1 (33-50%)		How much strength/ comfort do you get from your religion/spirituality right now?
Spiritual Index of Well-Being (SIWB; Daaleman & Frey, 2004)	12	5 (42%)	- There is not much I can do to help myself - I am overwhelmed when I have personal difficulties and problems - I don't know how to begin to solve my problems - There is not much I can do to make a difference in my life - There is a great void in my life at this time	

(Table 4.1 cont.)

Spiritual Well-Being Scale (SWBS; Ellison, 1983; Ellison & Smith, 1991)				
Existential Well-Being Scale	10	7 (70%)	- I feel that life is a positive experience - I feel very fulfilled and satisfied with life - I feel a sense of well-being about the direction my life is headed in - I don't enjoy much about life - I feel good about my future - I feel unsettled about my future - I feel that life is full of conflict and unhappiness	
Existential Well-Being Scale	10	3 (30%)		- I don't get much personal strength and support from my God - My relationship with God helps me not to feel lonely - My relationship with God contributes to my sense of well-being

(Table 4.1 cont.)

Spiritual Well-Being Questionnaire (SWBQ; Gomez & Fisher, 2003)	20	2 (10%)	How well do you feel the following statements describe your personal feelings over the last six months: - developing joy in life - developing inner peace	
WHOQOL Spirituality, Religion and Personal Beliefs (WHOQOL SRPB; O'Connell et al., 2006)	32	11 (34%)	- To what extent do you feel peaceful within yourself? - To what extent do you have inner peace? - To what extent do you feel a sense of harmony in your life? - How hopeful do you feel? - To what extent are you hopeful about your life?	- Connection to a spiritual being provides comfort/reassurance - Spiritual strength helps to feel happy in life - Faith contributes to well-being - Faith gives comfort in daily life - Faith gives strength in daily life - Faith helps to enjoy life

[a] Shannon et al. used a 15-item version of the DSES (Shannon et al., 2013). According to the developers of this questionnaire, their scale includes 15 items + one extra item that says "In general, how close do you feel to God?" (Underwood & Teresi, 2002). This extra item is not an SWB item, and is probably the item omitted by Shannon et al., which leads to the percentage of 4/15 = 27.

[b] A participant is classified with the Rush protocol as suffering from religious struggle (2 questions) or not (3 questions)

Exploratory survey

After having identified the scales that contain a substantial number of SWB or EWB items, we determined how many studies have been published that used these scales to predict EWB, distress, or quality of life. This will provide an indication of the extent to which contamination has occurred in the current body of evidence toward a relationship between spirituality and EWB.

We narrowed our search to eight well-cited scientific journals that are relevant to our field of research (health psychology and the psychology of religion and spirituality): the Annals of Behavioral Medicine, Journal of Behavioral Medicine, International Journal of Behavioral Medicine, Psycho-Oncology, Journal of Consulting and Clinical Psychology,

Supportive Care in Cancer, Journal for the Scientific Study of Religion, and Psychology of Religion and Spirituality. We have sought relevant references in Web of Sciences and PubMed till July 2014. In the health psychological journals we used the keywords SPIRIT* or RELIG* or FAITH in Title and/or Topic, and the name of the journal. In the other two journals the keywords we used were DISTRESS and/or WELL-BEING in Topics. Reviews, conference abstracts, letters, and qualitative studies were excluded. Also excluded were analyses in which spirituality was measured with a single item scale or if the items to the scale could not be found in any publication. Finally, studies were excluded in which the association between SWB and EWB scales was investigated for the purpose of validating the SWB scale. Included studies used the following scales as outcome measure:

- Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)
- Center for Epidemiologic Studies Depression scale (CES-D; Radloff, 1977)
- Profile Of Mood States (POMS; McNair, Lorr, & Drappelman, 1971)
- Beck Depression Inventory (BDI; Beck, Erbaugh, Ward, Mock, & Mendelsohn, 1961)
- Montgomery-Ashberg Depression Rating Scale (MADRS; Montgomery & Asberg, 1979)
- Positive and Negative Affect Schedule (PANAS; Watson, Clark, & Tellegen, 1988)
- Bradburn Affect Balance Scale (ABS; Bradburn, 1969)
- Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983)
- Mental Health Inventory (MHI-5; Berwick et al., 1991)
- Psychological distress subscale of the Psychological Adjustment to Illness Scale (PAIS; Derogatis, 1986)
- Mental Health Component Score of the Rand Medical Outcomes Study 12-item Health Survey (SF-36 or SF-12; Ware, Kosinski, & Keller, 1996)
- Emotional Well-Being scale of the Functional Assessment of Cancer Therapy - General or Spiritual (FACT-G or FACT-Sp; Cella, 1997)

Each of the three researchers of the present study independently determined whether individual studies should be included in this evaluation, based on two criteria: 1. The authors stated in the Abstract and/or Introduction that the purpose of the study is to determine the role of spirituality as a predictor of EWB (distress, quality-of-life, mood, adjustment) 2. In the Discussion section the authors considered the implications of their findings in terms of the influence or effect of spirituality on EWB.

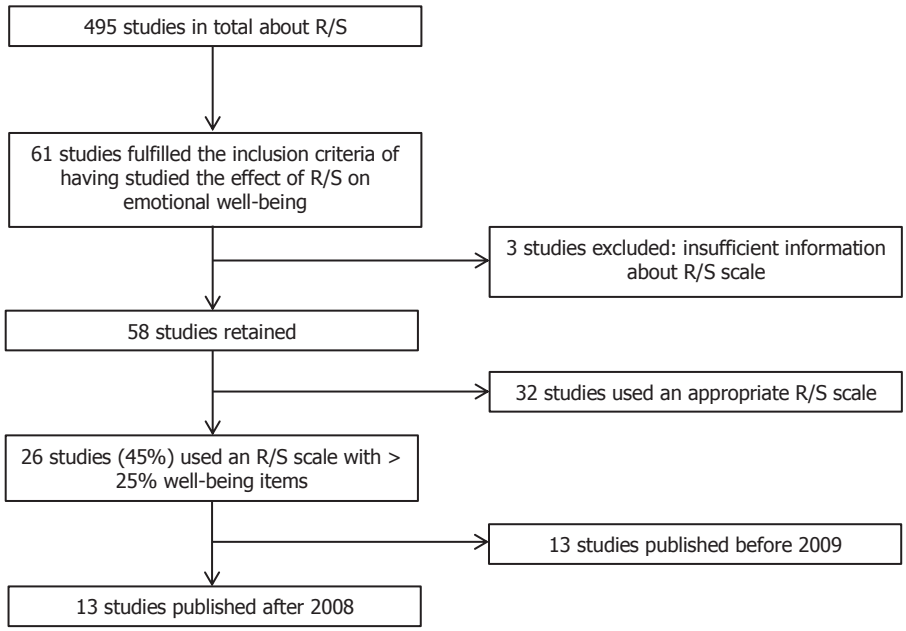
The search of the eight journals yielded 495 publications about spirituality, religion or faith; 61 were included on the basis of the above mentioned criteria, of which 3 could not be evaluated because of lacking information about the R/S scale used in these studies. Of the 58 remaining publications nearly half (26 studies) investigated the relationship in question using one of the eight spirituality questionnaires that we had identified as inappropriate for this purpose (see Figure 4.1). Here we present an overview of the frequency with which each questionnaire was used.

- The 15-item version of the DSES was used in one study (Shannon, Oakes, Scheers, Richardson, & Stills, 2013), the 16-item version in another study (Underwood & Teresi,

2002), and the 6-item version in two studies (Jackson & Bergeman, 2011; Shahabi et al., 2002).

- The FACIT-sp was used in 16 studies (Brady, Peterman, Fitchett, Mo, & Cella, 1999; Colgrove, Kim, & Thompson, 2007; Cotton, Levine, Fitzpatrick, Dold, & Targ, 1999; Edmondson, Park, Blank, Fenster, & Klis, 2008; Holt et al., 2011; Kim, Carver, Spillers, Crammer, & Zhou, 2011; Kim, Wellisch, Spillers, & Crammer, 2007; Kristeller, Sheets, Johnson, & Frank, 2011; Krupski et al., 2006; Mazzotti, Mazzuca, Sebastiani, Scoppola, & Marchetti, 2011; Nelson et al., 2009; Salsman, Yost, West, & Cella, 2011; Wassel Zavala, Maliski, Kwan, Fink, & Litwin, 2009; Whitford & Olver, 2012; Whitford, Olver, & Peterson, 2008; Yanez et al., 2009)
- Religious Coping Activities Scale – subscale Discontent was used in one study (Thompson & Vardaman, 1997)
- The Rush Protocol was applied in one study (King, Fitchett, & Berry, 2013)
- The SWBS was used in three studies (Laubmeier, Zakowski, & Bair, 2004; McCoubrie & Davies, 2006; Murphy et al., 2000)
- The SIWB was used in one study (Vespa, Jacobsen, Spazzafumo, & Balducci, 2011)
- The WHOQOL SRPB was used in none of the studies.

Figure 4.1. Flow chart of the results of the exploratory literature survey



R/S = Religion or spirituality.

Note In 2008, Koenig warned against using R/S scales that are heavily contaminated with questions assessing positive character traits or mental health (Koenig, 2008).

Discussion

The primary purpose of this paper was to remind the reader that spirituality questionnaires that contain items referring to spiritual or emotional well-being (SWB or EWB) should not be used to investigate the causal relationship between spirituality and EWB. In addition, we have provided an overview of spirituality questionnaires that contain a problematic number of SWB or EWB items and that would, therefore, be more appropriate for use as outcome measures than as predictors of EWB. To illustrate the extent of the problem for the body of evidence regarding the relationship between spirituality and EWB, we have explored how many studies on this topic that have been published in well-cited journals within the fields of health psychology and the psychology of religion and spirituality have used any of the eight questionnaires in the criticized manner. We found that this applied to about half of the studies. Notably, half of these studies had been published after 2008; the year Koenig vehemently warned against this practice (Koenig, 2008). In the years that followed, several others have also expressed their concern about the undesirable practice of using conceptually overlapping questionnaires to investigate the causal relationship between spirituality and EWB (Garssen et al., 2012a; Garssen et al., 2012b; Kapuscinski & Masters, 2010; Koenig, 2008; Migdal & MacDonald, 2013; Tsuang et al., 2007; Visser et al., 2010).

In this field full of pitfalls, it is important to avoid tautology when trying to demonstrate that spirituality predicts well-being, quality of life, or distress. To this end, our advice to researchers who wish to study this relationship is to not use the DSES, FACIT-Sp, the SIWB, the SWBS, or the WHOQOL SRPB as measures of spirituality. We stress that the problem lies not in the spirituality scales themselves, but in how they are used. Even though the Jarel includes only a small proportion of well-being items, we would also advise against its use as a predictor of well-being, because its psychometric qualities are insufficiently demonstrated (Monod et al., 2011; Sessanna, Finnell, Underhill, Chang, & Peng, 2011).

It should be noted that it was not our intention to provide an accurate, representative estimation of the number of studies that have used the criticized practice. We have chosen to include only journals that had published articles on R/S that had at least a moderately high impact factor, and were representative of our particular fields of study; health psychology (Supportive Care in Cancer, Annals of Behavioral Medicine, International J of Behavioral Medicine), clinical psychology (J Consulting Clinical Psychology), and the psychology of religion and spirituality (J Scientific Study of Religion, Psychology of Religion and Spirituality). Our aim was to provide an impression of whether or not the problem of contamination affects a substantial proportion of the body of evidence on the causal relationship between spirituality and EWB. Our finding that 26 of 58 studies in at least moderately high impact journals have used inappropriate measures of spirituality indicates that the problem has clearly eroded this field of research.

We also want to point out that the cut-off point of 25% that we used to determine which questionnaires contained too many items referring to EWB or SWB is not an absolute rule. The starting point in our simulation was the assumption of a near zero correlation

between the fictitious spirituality and EWB scales and a sample of one hundred persons. With larger samples, the correlation coefficients will become significant with less contamination of the spirituality scale. So, in order to avoid any risk of the bias discussed here, it is safer to use a questionnaire that contains no SWB or EWB items at all. Table 4.1 can help researchers to determine for themselves which questionnaire might be most appropriate for their purposes and their circumstance.

When it comes to an advice about which spirituality scale is suitable, more characteristics have to be taken into account than just the number of SWB or EWB items. Several spirituality scales do not contain such items, but they may suffer from a lack of sufficient psychometric quality. In an earlier publication, we have reviewed spirituality questionnaires in relation to psychometric properties, item formulation, suitability for use among non-religious individuals, and confusion with emotional well-being and distress (de Jager Meezenbroek et al., 2012b). To evaluate the formulation of the items, we determined whether the items are comprehensible, have a consistent meaning, and are answerable by all respondents. For instance, the words 'spiritual', 'spirituality', or 'spirit' will be differently understood by people, and should – in our view – be omitted in the wording of the items. In this review and on the basis of our current findings we conclude that the SWBQ is a suitable questionnaire, because it contains a small proportion of EWB items and we found that it has excellent psychometric properties (de Jager Meezenbroek et al., 2012b). The Spiritual Attitude and Involvement List (SAIL) may also be suitable if the Trust subscale is omitted. The remaining subscales of the SAIL do not include any well-being items and have sufficient psychometric qualities (de Jager Meezenbroek et al., 2012a).

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Part 2

Spirituality and adjustment to cancer

5

Does spirituality positively affect mental health? A systematic review of moderation and longitudinal main effects studies[5]

5 An adjusted version of this chapter is in preparation for publication as: Garssen, B, Visser, A., & Pool, G. (2014). *Does spirituality positively affect mental health? A systematic review and meta-analysis of longitudinal main effects studies.*

Abstract

Cross-sectional research has shown a positive association between religiousness/spirituality (R/S) and mental health. However, support for a causal influence of R/S can only be obtained in longitudinal studies, or by demonstrating that R/S reduces (buffers) the negative impact of stressful life events. In the current review 47 longitudinal main effects studies of R/S, and 26 moderation studies are summarized. Of the longitudinal studies 21% demonstrated a positive association between R/S and mental health. However, this proportion was reduced to 19% when only studies were included that used a reliable and valid R/S scale. Of the moderation studies, 56% found evidence for a buffering role of R/S, which was reduced to 40% when only studies were included that used a reliable and valid R/S scale. R/S was most often operationalized as public or private religious activities, religious guidance, or intrinsic religiosity. Of the direct effect studies that used a reliable and valid scale, 14% of the studies investigating religious activities found an effect on mental health, none of the studies investigating religious guidance found an effect, and 57% of the studies investigating intrinsic religiosity found an effect. Of the moderation studies that used a reliable and valid scale, 47% of the studies investigating religious activities found a buffering effect and none of the studies investigating intrinsic religiosity found an effect. The moderation studies on religious guidance did not use a reliable and valid scale. Therefore, we conclude that there is limited support for a causal effect of R/S on mental health.

Introduction

There is a research tradition of some 40 years into the role of religion and spirituality (R/S) in the maintenance of mental health. Several reviews and meta-analyses (see Textbox 5.1) have provided evidence in favor of such an association (Ano & Vasconcelles, 2005; Hackney & Sanders, 2003; Mytko & Knight, 1999; Sawatzky, Ratner, & Chui, 2005; Smith, McCullough, & Poll, 2003; Visser, Garssen, & Vingerhoets, 2010; Yonker, Schnabelrauch, & Dehaan, 2012).

These findings may suggest that the contribution of R/S to mental health has been proven beyond any reasonable doubt. However, there are a number of shortcomings to these reviews and meta-analyses. First, most of the studies included in these reviews and meta-analyses have used a cross-sectional design. Instead, longitudinal studies can provide a better indication for the existence of causal relationships, but so far they have shown mixed findings (Visser et al., 2010).

Second, the effect sizes used in the meta-analyses were correlation coefficients that were unadjusted for confounding variables (Ano & Vasconcelles, 2005; Hackney & Sanders, 2003; Sawatzky et al., 2005; Smith et al., 2003; Yonker et al., 2012). Indeed, it appeared that the conclusions in some of the reviewed studies were clearly different when they were based on zero-order correlations than when they were based on regression analyses that controlled for several demographic variables (Hebert, Zdaniuk, Schulz, & Scheier, 2009).

Textbox 5.1 Summary of meta–analyses on the association between R/S and mental health

The largest of the five meta-analyses included 147 studies and dealt with the association between R/S and depression (Smith, McCullough, & Poll, 2003). This meta-analysis reported a modest, but significant overall effect size of r = -.10.

A smaller-scaled meta-analysis, based on 34 recent studies, found the same overall effect size (Hackney & Sanders, 2003). The effect size was r = .12 for "life satisfaction", which included self-esteem, happiness, and so on, and was only r = -.02 for psychological distress.

A larger effect size of r = .34 was reported in a meta-analysis that determined the relationship between R/S and quality of life (Sawatzky, Ratner, & Chiu, 2005).

In another meta-analysis, the strength of the relationship between positive religious coping and positive adjustment was r = .33, and the strength of the relationship with negative adjustment was r = -.12 (Ano & Vasconcelles, 2005). Positive adjustment included a broad array of concepts, such as emotional well-being, optimism, personal growth, purpose in life, resilience, self-esteem, and quality of life. Negative adjustment included depression, anxiety, negative mood, distress, guilt, social dysfunction, suicidality, trait anger, and impairment.

A meta-analysis that focused on adolescents and young adults reported significant effects of R/S on depression (effect size r = .11) and well-being (effect size r = .15), though no effect on anxiety (Yonker, Schnabelrauch, & Dehaan, 2012).

Third, in some meta-analyses the outcome variables were rather extensive, including concepts broader than mental health like self-esteem, guilt, social dysfunction,

and anger (Ano & Vasconcelles, 2005; Hackney & Sanders, 2003; Sawatzky et al., 2005). In addition, some meta-analyses were restricted to religious coping (Ano & Vasconcelles, 2005) or focused solely on adolescents and young adults (Yonker et al., 2012).

In this review we provide an overview of studies on the prospective main effect and the moderation effect of R/S to determine whether it is likely that higher levels of R/S cause higher mental health, in accordance with a linear relationship between R/S and mental health. A few studies found a curvilinear association (King et al., 2007; Ronneberg, Miller, Dugan, & Porell, 2014; Schnittker, 2001); we will return to these exceptions in the Discussion section. In this context, the term 'moderation effect' refers to a buffering effect, which means that the deleterious effects of stressful life conditions on mental health will be reduced in people high in R/S, compared to people who are less religious and/or spiritual. Although a buffering effect is best demonstrated with a longitudinal research design, we also interpreted a cross-sectional buffering effect as an indication that R/S influences mental health. We did so, because in that case R/S explains variation in mental health in interaction with another variable, but mental health cannot explain variance in the interaction terms. So, with this outcome one may conclude that R/S played an active (causal) role in the adjustment to the stressful conditions. In contrast, a cross-sectional main relationship between R/S and mental health does not give any indication of the directionality of the association, so we only evaluated prospective longitudinal studies when examining the main effect of R/S on mental health.

In this review we will focus on outcome measures that reflect the presence of positive functioning - i.e. well-being, mental health, positive mood, life satisfaction - and/or a lack of negative functioning - i.e. distress or negative mood -, which are summarized in this review under the term "mental health". We have chosen to perform a systematic review instead of a methodologically stronger meta-analysis, because in this field the number of well-designed studies is relatively low and the studies lack unity in the types of R/S predictors, outcome variables, confounding variables, and measurement intervals used.

We consider this review to be explorative, which lies in the character of any review, but applies especially to this field of research, which has yielded a far from clear picture. A number of questions are evaluated in this review: (a) Does R/S have an effect on mental health, considering any R/S index as equally representative; (b) does the effect depend on the characteristics of the study, such as the type of sample, the age category of the sample, the sample size, and the length of follow-up; and (c) which aspects of R/S are more likely to be related to mental health?

Methods

We searched for articles in Web of Science and PubMed using the title keywords Spiritual*, Relig*, Faith, or (Meaning in the title and (Spiritual*, Relig* or Faith as topic keywords)) in combination with the title words Longitudinal, Prospective, Predictor*, Buffer*, Protective or Interact*. A critical p-value of .05 was applied to all reviewed results.

Exclusion criteria

Because we were interested in the positive contribution of R/S to mental health, we did not include studies and findings regarding negative aspects of religion, such as religious distress, negative religious coping or religious struggle (Park, Wortmann, & Edmondson, 2011). For this reason 'extrinsic religiosity' was not taken into account either, as it appeared to be positively related to depression (Smith et al., 2003). We also excluded three longitudinal, main effects studies in which changes in R/S and mental health were investigated in parallel, instead of prospectively (Braam et al., 2004; Gall, Guirguis-Younger, Charbonneau, & Florack, 2009; Krumrei, Mahoney, & Pargament, 2011). Three articles reported outcome data of the same study (Barton, Miller, Wickramaratne, Gameroff, & Weissman, 2013; Kasen, Wickramaratne, & Gameroff, 2014; Miller et al., 2012); we excluded the oldest and the newest article, because these reported outcomes of subgroups, but no overall beta coefficients.

Other exclusion criteria were: (1) Longitudinal study with a measurement interval less than 3 months, (2) longitudinal study without having controlled for baseline values of the outcome variable, (3) insufficient operationalization of R/S or mental health, (4) insufficient statistical tests, (5) less than 50 participants. The first four criteria were chosen for the following reasons:

Sub (1): Response bias may occur with a short interval, because participants might recall their previous responses. Furthermore, mental health appears to be rather stable (Levin, Markides, & Ray, 1996; Levin & Taylor, 1998). As a result of this criterion ten studies were excluded (Ai, Park, Huang, Rodgers, & Tice, 2007; Ai, Peterson, Bolling, & Rodgers, 2006; Carpenter, Laney, & Mezulis, 2012; King et al., 2013; Mascaro & Rosen, 2008; Pargament et al., 1994; Park, Cohen, & Herb, 1990; Park & Dornelas, 2012; Piedmont, 2004; Pressman, Lyons, Larson, & Strain, 1990). Moderation studies were included regardless of the measurement interval, so also cross-sectional studies were accepted.

Sub (2): There should be a correction for baseline mental health; studies that had not done so were excluded (Harris et al., 1995; Jang et al., 2013; Willits & Crider, 1988).

Sub (3) We excluded three studies that measured R/S with scales that include items on mental health (Colgrove, Kim, & Thompson, 2007; Ellison, 1983; Kim, Heinemann, Bode, Sliwa, & King, 2000; Yanez et al., 2009), because this may artificially inflate the association between R/S and mental health (de Jager Meezenbroek et al., 2012; Visser et al., 2010). An example of such a scale is the Spiritual Well-being Scale of the Functional Assessment of Chronic Illness Therapy (FACIT-Sp). We also excluded three studies in which a combined outcome measure was used that comprised more aspects of mental health than indicated in the Introduction, such as social role function (Park, Edmondson, Fenster, & Blank, 2008), vitality (Jim & Andersen, 2007), and satisfaction with work, community service and sport (Koenig & Vaillant, 2009). Several studies did not use a scale with proven reliability and validity to measure R/S. In order to preserve enough studies to allow for subgroup analyses, we chose to perform a sub-analysis on studies that used a psychometrically sound instrument

for the measurement of R/S, instead of excluding from all analyses the studies that did not use psychometrically sound instruments.

Sub (4) The statistical tests applied in five studies did not allow for a conclusion about a possible effect of R/S on mental health, and these studies were, therefore, excluded (Davis, Nolen-Hoeksema, & Larson, 1998; Hayward, Owen, Koenig, Steffens, & Payne, 2012; Idler, 1987; McIntosh, Silver, & Wortman, 1993; Son & Wilson, 2011).

Factors such as age, gender and educational level are known to be associated with both R/S and mental health and may, therefore, confound the results. However, we have also included studies without adequate control for these confounders.

Multiple testing and decisions about 'effect', 'limited effect', and 'no effect/only deleterious effect'

The significance of some results was unclear due to multiple testing. Many studies tested the effects of multiple R/S predictors on several mental health measures and sometimes in several subgroups, but failed to apply a correction for multiple testing. The only exceptions to this are the studies of Pössel et al. (2011) and Koenig (2007). A lack of correction for multiple testing makes it difficult to determine whether effects are chance findings or 'actual' effects.

On the other hand, we also did not want to be too strict, because then we would run the risk of dismissing an actual effect. Therefore, we applied the following rules: We concluded to an 'effect' when (a) at least 2/3 of the tests were significant and in the expected direction, or (b) when at least half of the tests were significant, in the expected direction, and a convincing explanation could be given for the lack of significant tests. We concluded to a 'limited effect' when (a) less than 2/3, but at least 1/3 of the tests was significant and in the expected direction, or (b) when less than 1/3 of the significant tests were not in the expected direction. Otherwise, the conclusion was 'no effect/only deleterious effects' (decisions on individual studies are described in the Appendix).

Categories of study characteristics

To be able to compare the studies included in our review, we have grouped R/S variables into categories. We attempted to stay as closely as possible to the names and categories used in the articles. The categories chosen are:

a. Public religious activities (which also includes church attendance, religious participation, and other forms of organized religiousness)
b. Private religious activities (which also includes prayer, reading religious books, and listening to religious radio/TV)
c. Support from church members (which also includes asking for prayer and religious support)
d. Religious guidance (which also includes finding religion important in one's life, commitment and religious salience)

e. Intrinsic religiosity (which also includes subjective religiousness, strength of belief in God or a spiritual power, and religious/spiritual identity)
f. Positive religious coping (which also includes seeking spiritual support)
g. Meaningfulness
h. Composite measures (which consist of public and/or private religious activities in combination with intrinsic religiosity).

Three types of samples were distinguished: population sample, somatically ill patients, and psychiatric patients or people at risk for depression. Age was divided into three categories: children or adolescents (inclusion criterion ≤ 18 years or mean age ≤ 18 years), adults (mean age ≤ 60 years), and elderly people (inclusion criterion ≥ 65 years or mean age ≥ 70 years). Studies were also divided into small-size (N ≤ 250) and large-size (N > 250) studies. Follow-up was divided into shorter than 1 year, 1 to 10 years, or longer than 10 years.

Table 5.1 Summary of the direct and buffering effects of R/S on mental health[1]

	All studies (%)	Studies with at least one reliable and valid R/S scale (%)
Longitudinal main effect		
effect	10 (21%)	7 (19%)
limited effect	4 (9%)	5 (6%)
no/deleterious effect	33 (70%)	27 (75%)
Total	47	36
Buffering effect		
effect	14 (56%)	6 (40%)
limited effect	0 (0%)	0 (0%)
no/deleterious effect	11 (44%)	9 (60%)
Total	25	15

[1] more information about the studies can be found in the Appendix

Results

Summary of the prospective, longitudinal studies

Our search yielded 108 longitudinal, main effects studies, of which 61 had to be rejected because they did not satisfy our criteria. The 47 prospective, longitudinal studies that were included in this review are summarized in Table 5.1 (each study is briefly described in the Appendix, Table A.1). Of these, 21% showed an effect of R/S factors on mental health. Some studies (9%) found limited effects, while in 70% of the studies no effect or a deleterious effect

of R/S was found. Taken together, this implies that, at best, 30% of the longitudinal studies found a potential positive direct effect of R/S factors on mental health.

A next step was to evaluate whether or not certain study characteristics influenced the findings (see Table 5.2). We were able to obtain information on the type of sample, age group, sample size, follow-up period, type of R/S category, and type of outcome variables.

Regarding the type of sample, an effect was found less often among somatically ill patients (21%) compared to population samples (31%). The number of effects was highest for psychiatric patients or people at risk for depression (38%). One would expect that R/S would especially affect the level of experienced distress in response to a major life event, such as bereavement, massive flooding or the attacks of 9/11. However, a convincing positive effect of R/S was found in only one out of four such studies.

Table 5.2 Main effects of R/S on mental health in longitudinal studies according to their characteristics

	effect	limited effect	no/deleterious effect	total number of studies
Sample characteristics [a]				
population sample	5 (31%)	3 (19%)	8 (50%)	16
somatically ill people	3 (21%)	1 (7%)	10 (71%)	14
psychiatric patients; people at risk of depression	3 (38%)	2 (25%)	3 (38%)	8
Total	11	6	21	38
people experiencing a major life event (bereavement, massive flooding or 9/11 attacks)	1 (25%)	0 (0%)	3 (75%)	4
Age group [b]				
children or adolescents	2 (25%)	1 (12%)	5 (63%)	8
adults	4 (22%)	0 (0%)	14 (78%)	18
elderly people	4 (36%)	1 (9%)	6 (55%)	11
Total	10	2	25	37
Sample size				
N ≤ 250	2 (11%)	4 (21%)	13 (68%)	19
N > 250	8 (29%)	1 (3%)	19 (68%)	28
Total	10	5	32	47
Follow-up				
shorter than 1 year	5 (28%)	2 (11%)	11 (61%)	18
1 to 10 years	6 (23%)	1 (4%)	19 (73%)	26
11 - 25 years	0 (0%)	0 (0%)	4 (100%)	4
Total	11	3	34	48 [c]

(Table 5.2 continued)

Type of R/S predictor [d]				
a. public religious activities	5 (19%)	1 (4%)	20 (77%)	26
b. private religious activities	0 (0%)	1 (10%)	9 (90%)	10
c. support from church members	0 (0%)	1 (50%)	1 (50%)	2
d. religious guidance	2 (22%)	2 (22%)	5 (56%)	9
e. intrinsic religiosity	3 (23%)	0 (0%)	10 (77%)	13
f. positive religious coping	3 (23%)	0 (0%)	10 (77%)	13
g. meaningfulness	1 (33%)	0 (0%)	2 (67%)	3
h. composite measure	2 (18%)	0 (0%)	9 (82%)	11
Total	16	5	66	87
Type of outcome variable [e]				
distress – continuous	8 (23%)	1 (3%)	26 (74%)	35
distress – dichotomous	2 (22%)	3 (33%)	4 (45%)	9
well-being	1 (17%)	1 (17%)	4 (67%)	6
life satisfaction	0 (0%)	0 (0%)	7 (100%)	7
Total	11	5	41	57

[a] Several studies used other type of samples than the three types and are not included in this table. The participants in the three studies of Koenig were both somatically ill and depressed

[b] Age was not indicated in all studies; age category of some studies did not fit into the categorization; Children or adolescents: inclusion criterion ≤ 18 years or mean age ≤ 18 years; Adults: mean age ≤ 60 years; Elderly people: inclusion criterion ≥ 65 years or mean age ≥ 70 years

[c] One study contained two follow-up periods

[d] Several studies tested more than one R/S predictor; Public religious activities also includes church attendance, religious participation, and other forms of organized religiousness; Private religious activities also includes prayer, reading religious books, and listening to religious radio/TV; Support from church members also includes asking for prayer and religious support; Religious guidance also includes finding religion important in one's life, commitment and religious salience; Intrinsic religiosity also includes subjective religiousness, strength of belief in God or a spiritual power, and religious/spiritual identity; Positive religious coping also includes seeking spiritual support; Composite measures consist of public and/or private religious activities in combination with intrinsic religiosity

[e] Several studies tested more than one outcome; some outcomes did not fit into the categorization; Distress also includes depression and anxiety

Concerning age, studies that focused on elderly people more often demonstrated a relationship between R/S and mental health (36%) than studies on adolescents (25%) or adults (22%).

Sample sizes varied widely, ranging from N = 68 to N = 8,318. An association was found more often in large-scaled studies (29%) than in small-scaled studies (11%).

The duration of follow-up also varied widely between studies, ranging from 3 months to 20 a 25 years. An effect of R/S on mental health was found most often with a shorter follow-up (< 1 year; 28%), and was never found in studies with a very long follow-up (> 10 years).

Several studies tested the effect of more than one R/S-variable. Therefore, this analysis was performed on the level of tests, not on the level of studies. In the 47 longitudinal studies, a total of 81 tests were performed for the various R/S concepts separately. No conclusions could be drawn about the effects of support from church members and meaningfulness, because of a lack of studies. For the remaining factors the number of convincing effects was less than 25%, and even zero for private religious activities. If the number of tests that found an effect or a limited effect are combined, the only R/S predictor that may be considered 'promising' in this rather lenient evaluation is religious guidance (44%).

Regarding the type of outcome variable, an effect of R/S was found more often for distress than for well-being; 23% of the tests on distress found an effect if a continuous measure was used and 22% of the studies found an effect on distress if a dichotomous measure was used, whereas only 17% of the studies on well-being found an effect. No effect of R/S on life satisfaction was found.

The influence of using an R/S scale with proven validity and reliability

Restriction to tests in which a valid and reliable scale was used led to the following results:

- Public and private religious activities measured with 1- or 2-item measures: 5 of the 36 tests (14%) showed a convincing effect (Chen et al., 2007; Ellison, Musick, & Henderson, 2008; Koenig, 2007; Law & Sbarra, 2009; McIntosh, Poulin, Silver, & Holman, 2011).
- Support from church members: No relationship in the only test that used a valid and reliable scale (Ellison et al., 2008).
- Religious guidance: No relationship in the two tests that used a valid and reliable scale (Dew et al., 2010; Sherman, Plante, Simonton, Latif, & Anaissie, 2009).
- Intrinsic religiosity: Of the seven tests for which a reliable and valid scale was used, an association was found in four tests (57%; Koenig, George, & Peterson, 1998; McIntosh et al., 2011; Pössel et al., 2011; Sun et al., 2012). No association was found in the three remaining tests (Dew et al., 2010; Hettler & Cohen, 1998; Koenig, 2007).
- Positive religious coping: Six of the eight tests that used an adequate measurement instrument showed no relationship between R/S and mental health (Dew et al., 2010; Fitchett, Rybarczyk, DeMarco, & Nicholas, 1999; Pargament, Koenig, Tarakeshwar, & Hahn, 2004; Sherman et al., 2009; Smith, Pargament, Brant, & Oliver, 2000; Trevino et al., 2010). Such a relationship was found in only two studies (Bosworth, Park, McQuoid, Hays, & Steffens, 2003; Reynolds, Mrug, Hensler, Guion, & Madan-Swain, 2014).
- Meaningfulness: A reliable and valid scale was used for one test, but an association was not demonstrated there (Dew et al., 2010).
- Composite measure: A valid and reliable scale was used in two studies (Perez, Little, & Henrich, 2009; Wink, Dillon, & Larsen, 2005), but a relationship was not demonstrated.

Taken together, of the 57 tests for which an R/S scale of proven reliability and validity was used only 11 tests (19%) showed a convincing relationship between R/S and mental health.

In terms of the number of *studies* that used at least one reliable and valid scale, 7 out of 36 studies (19%) showed an effect (See Table 5.1, last column).

Summary of the studies into the buffering effect of R/S

The buffering role of R/S implies that the negative effect of stressful life conditions on mental health is smaller among people high in R/S than among people low in R/S. The appropriate method for demonstrating such a moderation effect is to determine how much variation in mental health is explained by the product term of R/S by 'stressful conditions'.

In the studies we selected, it appeared that some investigators used correlation coefficients to test for buffering effects. This is not an appropriate procedure, because a difference in correlation coefficients between groups scoring high or low on R/S only reflects a difference in the strength of the relationship between R/S and mental health, not in the nature of the relationship. So, if the buffering effect was only determined with correlation coefficients and no convincing graphical support was presented we neglected the findings.

Our search yielded 43 publications that studied the buffering effect of R/S. Eighteen of these studies were rejected because the design was inadequate or the outcome variables fell outside our range. Of the 25 studies that were retained (the publication of Maton (1989) describes two studies), well over half (56%) reported a buffering effect and 44% found no effect or a deleterious (see Table 5.1). The studies are briefly described in the Appendix, Table A.2.

When considering the influence of study characteristics on the results, a buffering effect of R/S was found more often if the participants were somatically-ill persons (effect in 67% of the studies) compared to a population sample or a sample of students (57% and 40%, respectively; see Table 5.3). The sample sizes varied widely, ranging between N = 68 and N = 2,836. In studies with small samples a buffering effect was found somewhat more often than in large-scaled studies (67% versus 50%). There were no differences between cross-sectional or longitudinal studies (effect in 57% and 55% of the studies, respectively).

Whether or not R/S reduces the negative impact of stressors on mental health might depend on the type of stressor and/or the type of R/S predictor. When the stressor concerned the number of stressful life events, chronic strains or daily hassles R/S showed a buffering effect in less than half of the studies (43%). More studies found a buffering effect of R/S with specific stressors, namely the presence of somatic symptoms or discrimination (67% and 75%, respectively). When the R/S factor was intrinsic religion, a buffering effect was found only in a minority of the studies (17%). An effect was found more often if the R/S factor was public or private religious activities, or religious guidance (42%, 50% and 67%, respectively). There was not enough information on the possible buffering effects of other R/S factors.

Table 5.3 Studies on the buffering effects of R/S on mental health according to their characteristics

	effect	limited effect	no/deleterious effect	total number of studies
Sample characteristics [a]				
population sample	8 (57%)	2 (14%)	4 (29%)	14
students	2 (40%)	0 (0%)	3 (60%)	5
somatically ill people	2 (67%)	0 (0%)	1 (33%)	3
Total	12	2	8	22
Sample size				
N ≤ 250	6 (67%)	0 (0%)	3 (33%)	9
N > 250	8 (50%)	2 (13%)	6 (38%)	16
Total	14	2	9	25
Study design [b]				
cross-sectional	8 (57%)	2 (14%)	4 (29%)	14
longitudinal	6 (55%)	0 (0%)	5 (45%)	11
Total	14	2	9	25
Type of stressor				
number of stressful life events, chronic strains or daily hassles	6 (43%)	2 (14%)	6 (43%)	14
somatic problems	4 (67%)	0 (0%)	2 (33%)	6
discrimination (incl. HIV stigma and peer victimization)	3 (75%)	0 (0%)	1 (25%)	4
Total	13	2	9	24
Type of R/S predictor [c]				
a. public religious activities	5 (42%)	1 (8%)	6 (50%)	12
b. private religious activities	2 (50%)	2 (50%)	0 (0%)	4
d. religious guidance	6 (67%)	1 (11%)	2 (22%)	9
e. intrinsic religiosity	1 (17%)	0 (0%)	5 (83%)	6
f. positive religious coping	0 (0%)	0 (0%)	1 (100%)	1
g. meaningfulness	0 (0%)	0 (0%)	1 (100%)	1
h. composite measure	0 (0%)	0 (0%)	2 (100%)	2
Total	14	4	17	35

[a] Several studies used other types of samples and are not included in the table

[b] Some studies tested both a cross-sectional and a longitudinal relationship between R/S and mental health

[c] Several studies tested more than one R/S predictor; Some studies used other types of R/S predictors and are not included in the table; Public religious activities also includes church attendance, religious participation, and other forms of organized religiousness; Private religious activities also includes prayer, reading religious books, and listening to religious radio/TV; Religious guidance also includes finding religion important in one's life, commitment and religious salience; Intrinsic religiosity also includes subjective religiousness, strength of belief in God or a spiritual power, and religious/spiritual identity; Positive religious coping also includes seeking spiritual support; Composite measures consist of public and/or private religious activities in combination with intrinsic religiosity

Restriction to tests in which a valid and reliable scale was used

Frequency of church attendance and prayer were assumed to be reliably and validly measured, and 7 of the 15 tests with these measures showed a convincing effect (Bierman, 2006; Bradshaw & Ellison, 2010; Davis & Epkins, 2009; Ellison et al., 2008; Hettler & Cohen, 1998; Williams et al., 1991). In only one other test, on the effect of intrinsic religiosity, a reliable and valid scale was used, but no association with mental health was found (Pössel et al., 2011). This makes a total of 16 tests, of which 7 showed an association (44%). In terms of the number of studies that used at least one reliable and valid scale, 6 of the 15 studies (40%) showed an effect (See Table 5.1, last column).

Discussion

Reviews and meta-analyses have shown a consistent, though modest association between religiousness/spirituality (R/S) and mental health (well-being, mental health, negative and positive mood, life satisfaction, or the absence of distress). However, their findings were mainly based on cross-sectional studies and can, thus, provide little information on the nature of this relationship. The current paper is the first review that focuses exclusively on prospective, longitudinal studies on the main effect of R/S, and studies on the buffering effect of R/S. The aim of this review was to explore whether there is supportive evidence for a causal role of R/S in the maintenance or promotion of mental health, even during adversity.

A minority of the longitudinal studies included in our review convincingly showed an association between R/S and mental health (21%) and this number was reduced to 19% when only studies were included that used a reliable and valid R/S scale. Only a few study characteristics seemed to influence the results. More effects than in the total pool of studies were found among psychiatric patients/persons at risk for depression, population samples, and elder people. Less effects than in the total pool of studies were found if the sample size was low, follow-up was longer than 10 years, the R/S predictor was private religious activities, or the outcome measure was life satisfaction. The number of studies was too low for a conclusion with respect to the effects of support from church members and meaningfulness.

The co-occurrence of several study characteristics may have influenced the results. For example, when more large-scaled than small-scaled studies have included religious guidance as a predictor, but not the other aspects of R/S, the larger statistical power may have led to the greater proportion of significant tests for this R/S aspect compared to the others. We tested the effect of such co-occurrences with Chi Square tests. Because of the multitude of tests, we used an alpha of .01. It was found that studies with population sample were often large-scaled, had a long follow-up and infrequently tested the effect of religious coping, whereas studies with somatically ill patients were often small-scaled, had a short follow-up and frequently used religious coping as a predictor. Therefore, larger statistical power might be a reason that an effect of R/S on mental health was found relatively often in population samples and less frequently among somatically ill patients, and might also have somewhat covered the effects of religious coping.

More than half of the studies (56%) into the buffering role of R/S demonstrated a moderation effect, which was reduced to 40% if only the studies were included that used an R/S scale of proven reliability and validity. A buffering effect of R/S was most often seen among somatically ill patients, when the sample size was small, when the stressful conditions were the experience of somatic symptoms or discrimination, and when the R/S predictor was religious guidance/importance of religion. A buffering effect was observed less often than in the pool of studies among students, when the stressful condition was 'life events', and with all other R/S predictors than religious guidance/importance of religion.

In sum, we found little evidence for a causal relationship between R/S and mental health, although the outcome was somewhat more positive for the studies into the buffering effect. One might suppose that the role of R/S is so small that it mostly goes undetected, unless the number of participants is very high. Indeed, a main effect was found more often in large-scaled studies, though the reverse was true in the moderation studies.

A meta-analysis of thirty years ago (Bergin, 1983) already concluded that studies "do not provide much more than marginal evidence for a positive effect of religion". Fitchett et al. (1999) also concluded that "Our findings suggest that religion may be better understood as a covariate than a cause of better health and adjustment." (p. 346). Our review indicated that only religious guidance and finding religion important in one's life might have a causal effect on mental health and distress.

If R/S factors and mental health are not causally related, then how can we explain the fact that cross-sectional studies consistently demonstrated positive associations between these aspects? One possibility is that there is a common cause for R/S and mental health. Several studies have suggested that the variance in religiousness is to a large extent attributable to genetic factors (Smith et al., 2003), which seems to hold also for mental health (Lykken & Tellegen, 1996). A common factor might also be the environment in which children grow up; a warm and caring child-parent bond may be both a positive factor in the development of religious interests and a protective factor against depression (Smith et al., 2003). A third option concerns the possibility that high R/S is intrinsically related to mental health. For instance, one would expect that people who experience meaning in life, trust, and hope will also score high on well-being scales. This option predicts a high positive cross-sectional relationship, but no longitudinal association if the baseline values of mental health are taken into account. Indeed, in some of the reviewed studies the cross-sectional association was significant, whereas a longitudinal association was not found (Braam, Deeg, Poppelaars, Beekman, & van Tilburg, 2007; Dew et al., 2010; Levin & Taylor, 1998; Perez et al., 2009).

Limitations and future directions

An important problem of our and other reviews on R/S lies in the categorization of R/S aspects. It is a multifaceted concept and each concept may be differently related with mental health (Hackney & Sanders, 2003). We have tried to stay as closely as possible to the

actual description of the scales used by the authors of the reviewed studies, but we may have grouped together aspects that influence the outcomes in different ways. Furthermore, we did not include extrinsic religion and negative religious coping in our analysis, as it has been sufficiently demonstrated that these factors are related to less mental health (Ano & Vasconcelles, 2005; Sherman et al., 2009; Smith et al., 2003). Therefore, our review was restricted to R/S factors that are expected to be positively related to mental health.

In this review, we have focused on the linear relationship between R/S and mental health, meaning that mental health gradually increases with rising values of R/S. However, one may also expect that mental health is lowest among people who are somewhat uncertain about their spiritual attitude, implying that the highest values of mental health can be found among very religious/spiritual people and people who do not consider themselves religious/spiritual at all; in other words, those who are confident about their beliefs. Indeed, a few studies found a curvilinear association between R/S and mental health (King et al., 2007; Ronneberg et al., 2014; Schnittker, 2001). One study found the expected relationship: the chance of being depressed at follow-up was lower with high and low church attendance, compared to moderate attendance (Ronneberg et al., 2014). However, the other two studies found more depression with high and low religious salience (Schnittker, 2001), and with extremely high and low private religiosity (King et al., 2007). So, even the curvilinear relationship does not clearly support the general hypothesis of an unequivocal effect of R/S on mental health.

Another limitation of our review is that we constrained it to published studies written in English, of which the great majority came from the USA. Participants in most studies were Christian or atheist. Therefore, the findings may not be generalizable to other continents, cultures and religions.

Future studies on the causal effect of R/S factors should use a longitudinal or moderation design with sufficient time between the measurement of the predictor and the outcome to prevent response bias, but not so much time that a possible effect of R/S fades away. Future studies should also use reliable and valid scales, should have sufficient power, and should focus on predictors that seem most promising. In this regard, the experience of religious guidance or feeling that religion is important in one's life may be of special interest.

Ultimately, our review touches upon a basic question: Why should R/S be accompanied by higher well-being anyway? The essence of R/S seems to involve finding or using a framework to reflect on existential experiences, which can be deeply tragic or even cruel. So, the research question itself could be inappropriate to the nature of the phenomenon under study. The meta-analysis of Worthington, Hook, Davis, and McDaniel (2011) underscores this: Compared to secular psychotherapies, psychotherapies that include R/S content only have an added effect on spiritual outcome, not on psychological outcome.

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6

Does spirituality influence the negative impact of cancer-related stressors on mental health? Cross-sectional and longitudinal findings[6]

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Abstract

When diagnosed with cancer a patient has to cope with many stressors, which can lower their well-being and can cause great distress. Spirituality can play both a positive and a negative role in coping with cancer-related stressors. Therefore, we have investigated in two studies whether various aspects of spirituality influence adjustment to cancer-related stressors. Study 1 was a cross-sectional study among 216 cancer patients who received curative or palliative treatment. Study 2 was a 1-year longitudinal study among 383 cancer patients who were treated with curative intent only. In both studies, spirituality was measured with the Spiritual Attitude and Involvement List, which assesses six distinct but related aspects of spirituality. Hierarchical regression analyses were used to investigate the moderation effect of spirituality on the associations of fatigue, pain, and perceived life threat to well-being and distress. In study 1 no moderation effects were observed. In study 2, meaningfulness, acceptance and spiritual activities seemed to reduce the negative effect of fatigue on distress. Acceptance also seemed to reduce the negative effect of perceived life threat on distress. Caring for others seemed to strengthen the negative effect of perceived life threat on distress. Several aspects of spirituality seem to affect, either negatively or positively, how well a cancer patient copes with increases in fatigue and perceived life threat. Future longitudinal studies that utilize quantitative and qualitative methods are needed to replicate our findings and to further our understanding of the role of spirituality in the adjustment to cancer.

Introduction

For many people with cancer spirituality can be a resource for the psychological adjustment to this serious disease and its consequences, such as fatigue, pain, limitations in daily functioning, financial problems, or impediments when returning to work. Several reviews and meta-analyses on the relationship between spirituality and adjustment to stressors such as cancer have found that spirituality is positively associated with measures of psychological or emotional well-being, whereas it is negatively associated with measures of distress (Mytko & Knight, 1999; Sawatzky, Ratner, & Chiu, 2005; Smith, McCullough, & Poll, 2003; Visser, Garssen, & Vingerhoets, 2010). However, most of the studies included in these reviews and meta-analyses used a cross-sectional design. Such a design allows for several interpretations of a positive relationship between spirituality and adjustment: (1) spirituality leads to better adjustment, (2) spirituality and adjustment are two aspects of the same construct, or (3) adjustment affects spirituality. One way to gain insight into the directionality of the relationship between spirituality and adjustment is to investigate spirituality's role as a moderator.

We view spirituality as partly overlapping with (experienced) religiosity, and will use the term spirituality for both concepts in this paper. Spirituality is defined here as "one's striving for and experience of connectedness with the essence of life" (p. 142), which can be found in relationship with oneself, others, nature, and/or the transcendent (de Jager Meezenbroek et al., 2012).

So far, very few studies have investigated whether spirituality influences the effect of physical health problems on mental health. What's more, none of these studies have included cancer patients and they have investigated very limited aspects of spirituality. Dezutter, Robertson, Luyckx, and Hutsebaut (2010) found that the severity of pain was not related to life satisfaction among chronic pain patients who felt that religion was important in their lives, whereas it was negatively related with life satisfaction among those who did not find religion important. Chaudoir and colleagues (2012) found that people who experienced high HIV stigma but derived meaning and peace from their spirituality were less depressed than those who did not derive meaning and peace from their spirituality. Ai and Dunkle (1998), however, did not find a moderation effect of using prayer for help on the relationship between fatigue, shortness of breath or angina and distress among cardiac patients one year after surgery.

The first two years after the diagnosis of cancer have been found to be the most stressful (Mitchell et al., 2011; Mitchell, Ferguson, Gill, Paul, & Symonds, 2013) and fatigue and pain are frequently reported symptoms in cancer that have a great effect on emotional functioning (Arndt, Stegmaier, Ziegler, & Brenner, 2006; Clough-Gorr, Ganz, & Silliman, 2007; Henselmans, Helgeson, Seltman, & Vries, 2010; Kim et al., 2008; den Oudsten, de Vries, Steeg, Roukema, & van Heck, 2009; Vahdaninia, Omidvari, & Montazeri, 2010). In addition, studies have indicated that distress levels among cancer patients are positively associated with how threatening the patient perceives the cancer to be (Laubmeier, Zakowski, & Bair, 2004; Lynch,

Steginga, Hawkes, Pakenham, & Dunn, 2008; Mehnert, Lehmann, Graefen, Huland, & Koch, 2010; Wootten & Burney, 2007). Qualitative studies among cancer patients have indicated that spirituality helps them to find meaning in the occurrence of cancer in their lives and that it provides them with guidance on how to cope with this event (Aquino & Zago, 2007; van Leeuwen, Tiesinga, Jochemsen, & Post, 2007; Logan, Hackbush-Pinto, & De Grasse, 2006; Molzahn et al., 2012; Thomas & Retsas, 1999; Tulls Halstead & Hull, 2001). This sense of meaning and guidance may reduce any negative effect of cancer-related stressors such as pain, fatigue, and perceived life threat on mental health. On the other hand, these same qualitative studies have found that spirituality can also be an additional source of struggle when patients feel abandoned or punished by God, or when they are uncertain in their faith. Thus, various aspects of spirituality may have a very different influence on the adjustment to cancer-related stressors.

Therefore, we explore in two studies whether six distinct, but related aspects of spirituality influence the adjustment to cancer-related stressors. In study 1, we examine in a cross-sectional study whether spirituality influences the impact of pain and fatigue on the well-being and distress of cancer patients who are treated with curative or with palliative intent. In study 2, we examine during two 6-month periods after the diagnosis of cancer whether spirituality influences the impact of changes in pain, fatigue and perceived life threat on the well-being and distress of cancer patients treated with curative intent. No hypotheses were formed regarding which aspects of spirituality would be of importance and how, because of the dearth of moderation studies among cancer patients and the lack of consistency in operationalizations of spirituality in the existing moderation studies among people with a physical illness (Ai & Dunkle, 1998; Chaudoir et al., 2012; Dezutter et al., 2010).

Study 1

Methods

Participants

Participants were recruited at seven Dutch hospitals located close to or in the city of Utrecht. The inclusion criteria were: Being 18 years of age or older, being Dutch-speaking, and having been diagnosed with cancer more than two months before assessment. The patient's physician noted whether the patient was treated with curative or palliative intent; 152 participants were treated with curative intent and 64 participants were treated with palliative intent. The socio-demographic and medical characteristics of the participants are displayed in Table 6.1.

Table 6.1 Demographic and medical characteristics of the participants

	Study 1 (N = 216)	Study 2 (N = 444)
Mean age in years (SD)	59 (12.1)	59 (10.6)
Range	25-86	24-83
Gender (% female)	78	73
Having a partner (% yes)	81	80
Education (%)		
Low	32	19
Middle	40	41
High	27	40
Member of religious community (% yes)	68	62
Religious person? (%)		
Yes	54	53
No	41	42
Unsure	5	5
Spiritual person? (%)		
Yes	53	50
No	36	42
Unsure	11	8
Type of cancer (%)		
Breast	62	62
Colorectal	14	18
Lymph nodes	6	-
Gynecological	5	3
Lung	4	2
Prostate	3	12
Other	6	3
Mean time since diagnosis in months (SD)	30 (40)	3 (2.6)

Questionnaires

Table 6.2 shows the mean values and ranges of the study variables.

Fatigue was measured with the Dutch 4-item version of the Checklist Individual Strength (Alberts, Smets, Vercoulen, Garssen, & Bleijenberg, 1997). This shortened version is closely related to the often used, valid and reliable longer version of the Checklist Individual Strength (CIS; Vercoulen et al., 1994).

Pain was assessed with a visual analogue scale ranging from 1 “no pain at all” to 7 “the worst pain imaginable”.

To measure *spirituality* the Spiritual Attitude and Involvement List (SAIL) was used (de Jager Meezenbroek et al., 2012). The SAIL measures six aspects of spirituality: The experience of meaning and purpose in life, an attitude of acceptance toward life events, an attitude of compassion and responsibility for others, the experience of connectedness with nature, the occurrence of transcendent experiences, and the engagement in spiritual activities. The SAIL subscale Trust was not used in the current study, because it has shown limited construct validity (Visser, Garssen, & Vingerhoets, 2015). The reliability (internal consistency and test-retest reliability) and validity (factor-analytic validity and convergent and divergent validity) of the remaining six subscales have been sufficiently proven in five different samples (de Jager Meezenbroek et al., 2012).

Non-specific distress was assessed with the Dutch version of the Hospital Anxiety and Depression Scale (HADS; Spinhoven et al., 1997). Previous studies have indicated that spirituality is similarly associated with the two subscales of the HADS and its total score (McCoubrie & Davies, 2006; Noguchi et al., 2004). Therefore, in this study the HADS total score was used, which has shown good validity and reliability (Spinhoven et al., 1997).

Well-being was assessed with the Joy-in-Life subscale (JiL) of the Health and Disease Inventories (de Bruin & van Dijk, 1996). This is a Dutch questionnaire designed to assess the adaptation to cancer. The JiL showed reliability of $\alpha = .82$ in a sample of 460 cancer patients. Its convergent and divergent validity were satisfactory.

Potential *control variables* were age, gender, educational level, having a partner, serious life events, perceived prognosis, and time since diagnosis. *Serious life events* were assessed by asking the participants whether they had ever experienced a serious life event - for example illness other than cancer, a death, relationship problems, financial problems, the birth of a child, marriage, change of address, or retirement - and how often they had experienced such an event in their lives (1 or 2 times, 3 or 4 times, or 5 times or more, respectively). *Perceived prognosis* was assessed by asking patients to indicate how favorable they thought their prognosis was on a 5-point scale from “very favorable” to “very unfavorable”.

Statistical analyses

The scores on the HADS, JiL and pain scale were not normally distributed. Therefore, scores on the HADS were square-root transformed and scores on the JiL were inversely square-root transformed. To ensure that higher scores on the JiL indicated higher well-being, the transformed scores were subtracted from the highest possible score of 8. No transformation appeared successful for the scores on the pain scale, so the pain scores were categorized into ‘low’ (1 SD or more below the mean), ‘medium’ (between 1 SD below and above the mean), and ‘high’ (1 SD or more above the mean). Each category contain approximately one-third of the participants. Due to missing data on the outcome variables the analyses were based on N = 210.

Table 6.2 Mean values and ranges of study variables

	Mean study 1 (SD)	Mean study 2 (SD)	Possible range
Prognosis/Life threat [a]	2.2 (1.2)	15.0 (6.2)	1-5 | 9-34 [a]
Fatigue	4.0 (1.8) [b]	13.7 (6.8)	1-7
Pain	2.2 (1.3)	1.8 (0.9)	1-7 | 1-4
Meaningfulness	4.2 (0.7)	4.4 (0.7)	1-6
Acceptance	4.3 (0.7)	4.5 (0.7)	1-6
Caring for Others	4.4 (0.7)	4.7 (0.6)	1-6
Connectedness with Nature	4.6 (0.9)	4.7 (0.9)	1-6
Transcendent Experiences	2.5 (1.0)	2.4 (1.1)	1-6
Spiritual Activities	2.9 (1.2)	3.0 (1.3)	1-6
Well-being	4.0 (0.7) [b]	56.9 (10.2)	1-6 | 22-78
Distress	0.7 (1.6) [c]	9.0 (6.4)	0-4 | 0-34

[a] Used in Study 2

[b] Inverse square-root transformed scales

[c] Square-root transformed scale

As a preliminary step we have tested whether the curative and palliative cancer patients were comparable and could be combined in the analyses. The curative patients appeared to be younger than the palliative patients ($t = -4.18$, $p < .001$), to be more often female ($t = 4.92$, $p < .001$), to be closer to the time of diagnosis ($t = -2.26$, $p < .05$), and to view their prognosis as more favorable ($F = 164.68$, $p < .001$). Analysis of Covariance indicated that - controlling for age, gender, and time since diagnosis - there were no group differences on spirituality, pain, fatigue, well-being, and distress. Thus, it was decided that it was appropriate to combine the two samples into one group to increase power.

In order to further preserve power, only potential control variables that were related with both the dependent and the independent variables were selected for the analyses. These were the variables having a partner and perceived prognosis.

Hierarchical regression analyses were used to investigate whether spirituality moderates the relationship of fatigue and pain to distress and well-being. In step 1 the control variables were introduced in the model. In step 2 the predictor variables pain, fatigue, and one SAIL subscale were added. In step 3 the interaction terms of the specific SAIL subscale with fatigue and pain were introduced in the equation.

To reduce multi-collinearity between the interaction variables and their constituent variables, the scores of the constituent variables (except the categorical variable pain) were mean-centered. This was successful, except for the interaction terms of spirituality by pain; these were highly correlated with the constituent spirituality variables. Assumptions of linear

regression analysis regarding linearity and normal distribution were adequately met. When testing the moderation effects, we have chosen not to include all SAIL subscales in one analysis, because a weak but consistent effect of one interaction term may not be demonstrated if it shares explained variance with another interaction term. An overlap in explained variance was likely, as most interaction terms that included the same aggravating condition (fatigue and pain) were significantly related, despite mean-centering the constituent factors. Thus, a total of 12 hierarchical regression analyses were performed (six aspects of spirituality * two outcome variables).

All analyses were performed using SPSS 18.0 for Windows (PASW statistics, 2009). The significance level was set at alpha = .05. Following the recommendations of Armstrong (2014) and Steiner and Norman (2011), no correction for multiple testing was applied. Although a substantial number of tests are performed, which increases the risk of a Type I error, there is currently no knowledge on the moderating effect of spirituality on the relationships of pain and fatigue to well-being and distress. Adjustment for multiple testing would result in an increased risk of Type II errors, which would inhibit the ability of this study to generate hypotheses for future studies and, thereby, the development of our understanding of the role of spirituality in the adjustment to cancer.

Results

The findings are shown in Table 6.3. Only the interaction terms of fatigue with Meaningfulness and pain with Spiritual Activities explained a significant amount of additional variance in well-being (ΔR^2 = .02, p = .04 and ΔR^2 = .02, p = .05, respectively). The interaction term of Spiritual Activities by pain was not statistically significant (β = .28, p = .06) and, thus, was not explored further. Although the interaction term of Caring for Others by fatigue was statistically significant (see Table 6.3), it did not explain a significant amount of additional variance in well-being. Therefore, it was also not explored further. To explore the nature of the interaction between Meaningfulness and fatigue, simple slopes regressions were performed. The participants who scored 1 SD or more above the mean of Meaningfulness (n = 47) were compared to those who scored 1 SD or more below the mean (n = 53). No moderation effect was observed: The relationship between fatigue and well-being was similar between participants scoring high on Meaningfulness (β = -.41, p = .001) and low on Meaningfulness (β = -.59, p < .001). A main effect on well-being was observed for all aspects of spirituality except Spiritual Activities.

None of the interaction terms explained a significant amount of additional variance in distress. A main effect on distress was observed for Meaningfulness and Acceptance.

Table 6.3 Study 1: Summary of cross-sectional hierarchical regression analyses

	ΔR²	B [a]	95% CI	β [a]	p [a]
		Well-being			
Step 1	.08				
Having a partner		0.57	0.20, 0.95	.20	.003
Perceived prognosis		-0.18	-0.30, -0.06	-.19	.004
Step 2	.28, .39				
Having a partner		0.27, 0.52	-0.03, 0.83	.09, .18	.001, .08
Perceived prognosis		-0.09, -0.11	-0.19, 0.01	-.10, -.12	.03, .06
Fatigue		-0.07, -0.08	-0.25, 0.08	-.44, -.52	< .001
Meaningfulness		0.52	0.37, 0.68	.36	< .001
Acceptance		0.43	0.27, 0.60	.28	< .001
Caring for Others		0.38	0.20, 0.55	.23	< .001
Connectedness with Nature		0.15	0.02, 0.29	.13	.03
Transcendent Experiences		0.13	0.003, 0.26	.11	.04
Step 3	.003, .02				
Having a partner		0.27, 0.52	-0.03, 0.84	.09, .18	.001, .07
Perceived prognosis		-0.09, -0.12	-0.22, 0.10	-.10, -.13	.03, .07
Fatigue		-0.06, -0.08	-0.08, -0.06	-.40, -.52	< .001
Meaningfulness		0.64	0.25, 1.03	.44	.002
Acceptance		0.55	0.12, 0.98	.35	.01
Meaningfulness * Fatigue		-0.03	-0.05, -0.01	-.13	.02
Caring for others * Fatigue		-0.02	-0.05, 0.00	-.11	.05
		Distress			
Step 1	.08				
Having a partner [b]		-0.39	-0.76, -0.03	-.14	.04
Perceived prognosis		0.22	0.10, 0.34	.24	< .001
Step 2	.27, .33				
Having a partner [b]		-0.21, -0.35	-0.53, 0.10	-.08, -.13	.03, .18
Perceived prognosis		0.15, 0.16	0.05, 0.26	.16, .18	.002, .004
Fatigue		0.07, 0.08	0.05, 0.09	.46, .50	< .001
Meaningfulness		-0.27	-0.43, -0.10	-.19	.002
Acceptance		-0.36	-0.52, -0.19	-.23	< .001
Step 3	.00, .01				
Having a partner [b]		-0.21, -0.35	-0.53, 0.10	-.08, -.13	.03, .19
Perceived prognosis		0.14, 0.16	0.04, 0.26	.16, .18	.002, .01
Fatigue		0.07, 0.08	0.05, 0.10	.44, .51	< .001
Acceptance		-0.48	-0.91, -0.05	-.31	.03

Note Only statistically significant results at p ≤ .05 are displayed

[a] Values vary, because they are dependent on the specific aspects of spirituality with which they are combined

[b] Having a partner: 1 = no, 2 = yes

Study 2

In the cross-sectional study described above we found that fatigue, but not pain, was related to the adjustment of cancer patients and that spirituality did not influence this relationship. However, one may argue that it is a change in physical symptoms rather than their static level that requires adjustment and that spirituality may be particularly important as a coping resource when a person actively needs to adjust to such a change in circumstances. Therefore, in this study we use a longitudinal design to investigate whether spirituality moderates the relationship of changes in pain and fatigue to adjustment, during two time-periods of 6 months. In addition, we investigate in this study whether spirituality moderates the influence of perceived life threat on adjustment.

Methods

Participants

Participants were recruited from four hospitals and two radiotherapy institutions in the Netherlands, by a member of the medical staff. Patients were eligible for participation if they were 18 years of age or older, were Dutch-speaking, were treated for cancer with curative intent, were receiving surgery or radiotherapy as primary treatment for cancer, were within two months after the start of treatment, and were not diagnosed with a psychiatric disorder or a brain tumor.

At the first assessment (T1) 460 patients provided informed consent. The second assessment (T2) took place after six months, to which 408 people responded (retention rate = 89%). After another six months, the final assessment took place (T3). This third questionnaire was filled out by 383 participants (retention rate compared to T1 = 83%). The main reasons for attrition during the study were death (N = 19), non-response (N = 16), no longer feeling motivated to fill out the questionnaires (N = 22), having developed psychological problems (N = 2), or having become too physically ill (N = 2). In addition, 16 participants were removed from the study, because it was unlikely that they were treated with curative intent. Socio-demographic and medical characteristics of the sample are presented in Table 6.1.

Questionnaires

Table 6.2 shows the mean values and ranges of the study variables.

Fatigue, serious life events, spirituality, well-being, and distress were assessed with the same instruments as in study 1, except that the patients were now asked whether they had experienced a serious life event in the past 6 months as opposed to ever in their lives.

The *pain* scale from the Dutch version of the European Organization for Research and Treatment of Cancer, Quality of Life Questionnaire-C30, version 1 (EORTC-QLQ-C30; Aaronson et al., 1993) was used to assess pain. In the current study we used the average score of the two items (Fayers, Aaronson, & Bjordal, 1999).

To assess *perceived life threat*, the Perceived Life Threat Scale (Laubmeier et al., 2004) was used, which was translated to Dutch for use in this study by AV.

The potential *control variables* in this study were age, gender, having a partner, having children, the number of children, educational level, having a paid job, type of cancer, time since diagnosis, the presence of metastases, still being in treatment at T2 or T3, time since the end of treatment, type of treatment, comorbidity, type of medication used (pain, sleep, anti-anxiety, anti-depressant, other), type of additional care received (pastoral care worker, social worker, psychologist, complementary or alternative care, other), and having experienced a serious life event other than cancer during the previous 6 months.

Statistical analyses

All variables were approximately normally distributed, so no transformations were applied.

Hierarchical regression analyses were used to investigate the moderation effect of spirituality on the relationships of changes in fatigue, pain, and perceived life threat to well-being and distress. This was investigated separately for the intervals from T1 to T2 and from T2 to T3.

In step 1 of the regression analyses the control variables were entered in the model. In order to preserve power, only socio-demographic and medical control variables that were related with either the dependent or the independent variables at $r \geq .20$ were selected for the analyses. These were the medical variables receiving radiotherapy, receiving chemotherapy, time since the end of treatment, using pain medication, and using sleep medication as assessed at either T2 or T3. In step 2 the predictors of change in pain, in fatigue, and in perceived life threat, and one aspect of spirituality as assessed on either T1 or T2 were entered. In step 3 the interaction terms of change in pain, in fatigue, and in perceived life threat by each aspect of spirituality were added. The outcome variables were the change in well-being or distress during each interval.

As in study 1, all subscales of the SAIL were investigated separately to enhance power. The predictor variables were mean-centered to reduce multi-collinearity. Assumptions of linear regression analysis regarding linearity, homoscedasticity, and multivariate normal distribution were adequately met.

All analyses were performed using SPSS 19.0 for Windows (IBM Company, 2010). The significance level was set at alpha = .05. As in Study 1, no correction for multiple testing was applied.

Results

T1 – T2

The results are displayed in Table 6.4. None of the interaction terms added a significant amount of variance to the explanation of well-being, but the interaction term of change in fatigue with Meaningfulness added a marginally significant amount of variance to the explanation of distress ($\Delta R^2 = .03$, $p = .05$).

Table 6.4 Study 2: Summary of hierarchical regression analyses of interval T1 – T2

	ΔR²	B [a]	95% CI	β [a]	p [a]
		Change in well-being			
Step 1	.08				
Sleep medication [b]		-4.97	-7.72, -2.21	-.22	< .001
Step 2	.11, .12				
Sleep medication [b]		-4.80, -5.05	-7.69, -2.20	-.21, -.23	< .001
Change in fatigue		-0.28, -0.30	-0.45, -0.14	-.25, -.27	< .001
Step 3	.01, .02				
Sleep medication [b]		-4.81, -5.23	-7.90, -2.20	-.22, -.23	< .001
Change in fatigue		-0.28, -0.32	-0.47, -0.13	-.25, -.29	< .001
Caring for others		1.37	0.05, 2.69	.12	.04
Connectedness with nature * change in perceived life threat		0.22	0.01, 0.44	.12	.04
		Change in distress			
Step 1	.10				
Radiotherapy [b]		2.35	0.87, 3.83	.19	.002
Sleep medication [b]		2.56	0.85, 4.28	.18	.004
Step 2	.10				
Radiotherapy [b]		1.35, 1.56	-0.12, 3.01	.11, .13	.04, .07
Sleep medication [b]		2.51, 2.61	0.87, 4.27	.18, .19	.002, .003
Change in fatigue		0.13, 0.14	0.04, 0.24	.19, .21	.002, .005
Change in pain		0.76, 0.79	0.06, 1.49	.14, .15	.03
Change in perceived life threat		0.12	-0.001, 0.24	.12	.05
Step 3	.003, .03				
Radiotherapy [b]		1.36, 1.61	-0.13, 3.10	.11, .13	.03, .07
Sleep medication [b]		2.54, 2.73	0.85, 4.38	.18, .19	.001, .003
Change in fatigue		0.13, 0.16	0.04, 0.25	.18, .22	.001, .008
Change in pain		0.68, 0.97	-0.03, 1.69	.12, .18	.008, .06
Change in perceived life threat		0.12, 0.14	-0.001, 0.26	.13, .14	.02, .05
Meaningfulness * Change in fatigue		-0.13	-0.24, -0.02	-.15	.02
Caring for others * Change in perceived life threat		0.201	0.01, 0.40	.13	.04

Note Only statistically significant results at p ≤ .05 are displayed

[a] Values vary, because they are dependent on the specific aspects of spirituality with which they are combined

[b] Radiotherapy and Sleep medication: 0 = no, 1 = yes

Simple slopes regression analyses were performed to explore the nature of this interaction. A buffering effect was observed when comparing the participants who scored 1 SD or more above the mean on Meaningfulness to those scoring 1 SD or more below the mean: Change in fatigue was not significantly related to distress among the participants who scored high on Meaningfulness (n = 47; β = .20, p = .18), whereas this positive relationship was significant among participants scoring low on Meaningfulness (n = 72; β = .29, p = .01).

T2 – T3

The results are displayed in Table 6.5. The interaction terms did not explain a significant amount of additional variance in well-being, but the interaction terms of Acceptance, Caring for Others, and Spiritual Activities explained a significant amount of additional variance in distress (ΔR^2 = .03, p = .02; ΔR^2 = .03, p = .01; ΔR^2 = .04, p = .01, respectively). Acceptance and Spiritual Activities interacted with fatigue. In addition, Acceptance and Caring for Others interacted with perceived life threat. Though the interaction term of Meaningfulness by fatigue was also significant, it did not explain a significant amount of variance in distress. Thus, it was not explored further.

Simple slopes regressions were performed to investigate the nature of the interactions. The participants who scored 1 SD or more above the mean on Acceptance (n = 63), Caring for Others (n = 49), and Spiritual Activities (n = 60) were compared to those scoring 1 SD or more below the mean on these aspects of spirituality (n = 56, n = 44, n = 76, respectively). Acceptance buffered the effects of change in fatigue and change in perceived life threat on distress: Fatigue and perceived life threat were not related to distress among those scoring high on Acceptance (β = .12, p = .33 and β = .20, p = .12, respectively), whereas these positive relationships were significant among those scoring low on Acceptance (β = .38, p = .003 and β = .30, p = .02, respectively). Caring for Others increased the negative effect of change in perceived life threat on distress: The relationship between change in perceived life threat and distress was significant and positive among participants scoring high on Caring for Others (β = .57, p < .001), whereas it was non-significant and negative among those scoring low on this aspect of spirituality (β = -.19, p = .20). Spiritual Activities showed a buffering effect: Change in fatigue was not related to distress among participants scoring high on Spiritual Activities (β = .20, p = .12), whereas it was positively associated with change in distress among participants scoring low on Spiritual Activities (β = .44, p < .001).

Table 6.5 Study 2: Summary of hierarchical regression analyses of interval T2 – T3

	ΔR²	B [a]	95% CI	β [a]	p [a]
		Change in well-being			
Step 1	.02, .03				
Pain medication [b]		1.57, 1.86	-0.96, 3.59	.11, .13	.03, .07
Step 2	.11, .12				
Pain medication [b]		1.39, 1.67	-0.27, 3.33	.10, .12	.05, .10
Change in fatigue		-0.25, -0.27	-0.39, -0.13	-.25, -.27	< .001
Change in perceived life threat		-0.22, -0.23	-0.41, -0.05	-.15, -.16	.01, .01
Step 3	.001, .01				
Pain medication [b]		1.41, 1.71	-0.27, 3.40	.10, .12	.05, .10
Change in fatigue		-0.25, -0.29	-0.42, -0.12	-.25, -.29	< .001
Change in perceived life threat		-0.19, -0.25	-0.43, -0.04	-.04, -.17	.008, .04
		Change in distress			
Step 1	.015				
Step 2	.16, .17				
Change in fatigue		0.16, 0.17	0.08, 0.25	.25, .26	< .001
Change in pain		0.62, 0.65	0.02, 1.25	.12, .13	.03, .04
Change in perceived life threat		0.19, 0.20	0.05, 0.32	.20, .21	< .001, .001
Acceptance		0.20	0.06, 1.34	.12	.03
Step 3	.008, .04				
Change in fatigue		0.16, 0.20	0.08, 0.28	.24, .30	< .001
Change in pain		0.63, 0.75	0.04, 1.36	.13, .15	.02, .04
Change in perceived life threat		0.16, 0.23	0.05, 0.34	.16, .23	< .001, .006
Acceptance		0.63	-0.01, 1.26	.11	.05
Meaningfulness * Change in fatigue		-0.13	-0.24, -0.02	-.15	.02
Acceptance * Change in fatigue		-0.11	-0.22, -0.003	-.12	.04
Acceptance * Change in perceived life threat		-0.14	-0.29, 0.00	-.11	.05
Caring for others * Change in perceived life threat		0.26	0.11, 0.42	.20	.001
Spiritual activities * Change in fatigue		-0.10	-0.16, -0.05	-.22	< .001

Note Only statistically significant results at p ≤ .05 are displayed

[a] Values vary, because they are dependent on the specific aspects of spirituality with which they are combined

[b] Pain medication: 0 = no, 1 = yes

General discussion

In the present cross-sectional and longitudinal studies we have explored whether spirituality influences the adjustment to cancer-related stressors. At a cross-sectional level no moderation effect of spirituality was observed. However, all aspects of spirituality except the engagement in spiritual activities were directly positively related to well-being, and the experience of meaning and purpose in life and the attitude of acceptance were directly negatively related to distress.

At a longitudinal level several moderation effects of spirituality were observed. The experience of meaning and purpose in life seemed to reduce the negative effect of fatigue on distress during the first six months after the start of treatment. Between 6 and 12 months after the start of treatment, the attitude of acceptance and the engagement in spiritual activities seemed to reduce the negative effect of fatigue on distress. The attitude of acceptance also seemed to reduce the negative effect of perceived life threat on distress during this interval. Experiencing life as meaningful and purposeful and having an attitude of acceptance toward both the good and bad in life. In contrast, the attitude of compassion and responsibility toward others seemed to magnify the negative effect of perceived life threat on distress between 6 to 12 months after the beginning of cancer treatment.

The direct and moderation effects of meaningfulness, acceptance, caring for others, and spiritual activities may be explained by the meaning-making coping model of Jeserich (2014). High scores on these aspects of spirituality represent a situation in which a person has a strong sense of self-coherence or identity, she experiences her life view as credible and consistent, and negative life events are congruent with her life view. This helps the person to maintain her sense of confidence about the comprehensibility, manageability and meaningfulness of life and her mental health. In contrast, when the person who scores high on caring for others experiences a high threat to her life, she may feel that the well-being of her loved ones and her own purpose in life are at risk (incongruence and a threat to identity), which increases her feelings of distress.

However, only 7 of the 60 interaction effects that we tested in studies 1 and 2 added a small but significant amount of variance to the explanations of well-being or distress. Therefore, we examined whether our analyses had enough power to detect interaction effects that added a moderate proportion of explained variance of $f^2 = .075$ (R^2 change ≈ .070). We performed post-hoc power analyses using the program G*power 3.1 (Faul, Erdfelder, Lang, & Buchner, 2007). This indicated that the power of the studies was excellent. The statistical power of study 1 was .95, given a two-tailed α-level of .05, N = 208, 2 predictors, and 7 predictors in total. The statistical power of study 2 was .97 for the analyses of the interval between T1 and T2 (N = 253) and .98 for the analyses of the interval between T2 and T3, given a two-tailed α-level of .05, 3 predictors, and 12 predictors in total. So, it seems unlikely that any potential moderation effect of spirituality was missed.

Most effects of spirituality were found in study 1 and in the second time-period of study 2. This may be explained by the phase of the cancer trajectory that the patients were in.

In study 1, the patients had been diagnosed with cancer a median of 15 months before study enrollment. Although 66% indicated to have received treatment for cancer in the month before enrollment it might be expected that the urgency of the treatment had abated and that the participants had resumed their daily routines. In study 2, 60% of the participants had completed active treatment on average 4.5 months before T2 and an additional 3% had completed active treatment at T3. So these participants might be expected to be in the full swing of re-entry into "normal" life. Henselmans, Coyne, Sanderman, de Vries, and Ranchor (2009) reported that, compared to healthy controls, breast cancer patients showed elevated levels of non-specific distress – on which we found most effects – from shortly after the diagnosis up until 6 months after active cancer treatment. Especially after treatment, distress may be the result of the existential challenge of rediscovering or finding a new fulfillment in life and reestablishing one's identity (van Leeuwen et al., 2007; Tulls Halstead & Hull, 2001). Spirituality can play an important role in this process, because one of its primary functions in daily life seems to be to provide a system of meaning from which a person derives a sense of identity and interprets his life and its events (James & Wells, 2003; Park, 2007).

Two limitations to the present study should be considered. First, we examined the relationships between concurrent assessments of the predictor and dependent variables, either as static levels or as change over time. A true moderation effect is best demonstrated when the predictor variables occur and are assessed prior to the dependent variables. However, considering the nature of the variables under study, we felt that using concurrent assessments was warranted. Especially fatigue and pain are expected to fluctuate frequently and to have a short-term effect on adjustment. So, in order to detect an effect of pain and fatigue on adjustment they need to be measured very closely in time.

Second, using a convenience sample in both studies may have biased the findings, because the samples may have consisted of mainly spiritual people with relatively few physical and mental health problems due to cancer. However, in both studies 63% of the participants indicated to be either religious, spiritual, or both, which is very similar to the finding of Berghuijs, Pieper, and Bakker (2013) that 61% of their Dutch population sample considered themselves religious and/or spiritual. Thus, there seems to be no selection bias based on the level of spirituality. Selection bias based on health cannot be ruled out, because we have not gathered information on the physical and mental health status of the people who refused participation in both studies. The participants who dropped out of study 2 (n = 61) had reported significantly more fatigue and pain at T1 than those who completed all three assessments. However, the two groups did not differ on baseline spirituality, distress or well-being, making any bias in the results due to selective attrition less likely.

To conclude, our findings suggest that meaningfulness, acceptance, caring for others, and spiritual activities influence the relationships of fatigue and perceived life threat to distress among cancer patients. Pain was not related to adjustment to cancer. Though spirituality affected the relationship between cancer-related stressors and distress, no such effect was found for well-being. The moderation effects were only found when we examined

changes in the stressors, instead of static levels, and most of the effects occurred between 6 and 12 months after the start of cancer treatment. To the best of our knowledge, this is the first study to examine the moderating role of spirituality among cancer patients, so many questions are left unanswered: How do the aspects of spirituality affect the experiences of fatigue and life threat? Why do they affect the relationship of these stressors to distress, but not well-being? Why did the effect show up especially between 6 and 12 months after the start of treatment? Future studies that use a longitudinal design with more measurement moments and that use both quantitative and qualitative methods are needed to further our understanding of the role that spirituality plays in the adjustment to cancer.

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7

Spirituality and the psychological adjustment to cancer: A prospective, typological approach[7]

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Abstract

To do more justice to the different ways in which people are spiritual, it might be useful to investigate the relationship between spirituality and adjustment to cancer from a typological perspective. Therefore, we have investigated whether people who self-identify as religious (R), spiritual (S), both (R+S), or neither (-R-S) differ in their adjustment to cancer during two 6-month periods, and whether any differences in adjustment may be explained by differences in coping resources or in coping style. Assessments took place within 2 months after the diagnosis of cancer (n = 444), 6 months later (n = 408), and another 6 months later (n = 383). Hierarchical regression analysis was used to examine group differences in adjustment and the mediating role of coping resources and coping style. The groups did not differ in adjustment to cancer. The non-spiritual groups (-R-S and R) were less inclined than the spiritual groups (S and R+S) to use the coping styles seeking social support and active coping. To conclude, religious/spiritual self-identification does not predict longer-term adjustment to cancer. The present study is the first longitudinal study to investigate the association between a typology of spirituality and adjustment to cancer. For future studies we advise using a typology that is based on the degree to which spirituality is integrated in the life of the person. We also advise the use of outcome measures that are disease-specific and meaning- or growth-oriented to assess adjustment, instead of measures of general well-being or distress as used here.

Introduction

The diagnosis and treatment of cancer can have a great negative impact on the mental health of people. Nevertheless, the majority of people adjust well to this serious life event (Krebber et al., 2014; Mitchell et al., 2011). Several factors have been positively associated with the adjustment to cancer, for example social support and optimism (Carlson, Waller, Groff, Giese-Davis, & Bultz, 2013; Hodges & Winstanley, 2012). Spirituality and religion (S/R) have also been found to be positively associated with adjustment to cancer in a number of studies (Schreiber & Brockopp, 2012; Visser, Garssen, & Vingerhoets, 2010). However, we still do not fully understand how and why this relationship exists, among others, because the measures used in these studies do not adequately represent S/R as the complex meaning system that it is. Several authors have suggested that it might be more useful to approach S/R from a typological perspective, because this approach might do more justice to the different ways in which people are spiritual/religious and it might provide more information on how the various spiritual/religious behaviors, beliefs, attitudes, and experiences interact to impact (mental) health (Moberg, 2002; Park, 2007).

One typology, which has emerged within the general population, differentiates between people who are 'neither religious nor spiritual', 'religious, but not spiritual', 'spiritual, but not religious', and 'both religious and spiritual' (Gall, Malette, & Guirguis-Younger, 2011; Saucier & Skrzypinska, 2006). Studies suggest that this typology distinguishes between different life views. For example, in a large sample of the Dutch general population, Berghuijs, Pieper, and Bakker (2013) found that the people who self-identified as both religious and spiritual were most inclined to value spiritual transformation, to believe in monism (for example, "everything is connected to everything"), and to endorse traditionally religious beliefs, experiences, or practices (such as, orthodox Christian beliefs, religious transcendent experiences, religious affiliation, and prayer); the only religious were highly inclined, though less than the both religious and spiritual, to endorse traditional religious beliefs, experiences, or practices; the only spiritual were most inclined to endorse a belief in karma and in paranormal issues, but were less inclined to endorse traditionally religious beliefs, experiences, or practices; and the neither religious nor spiritual were least inclined to endorse either religious or spiritual beliefs, experiences, or practices.

It might be more informative to use a typology such as the above when investigating the relationship between S/R and adjustment to cancer than to use the current measures of S/R, because these measures assess the various aspects of S/R in isolation. Instead, several authors have argued that the aspects of S/R interact in complex ways to affect mental health (James & Wells, 2003; Moberg, 2002; Pargament, 2002; Park, 2007). The few studies investigating this hypothesis in the context of physical health seem to support it. For example, Park, Wortmann, and Edmondson (2011) found among coronary heart disease patients that the negative effect of religious struggle (having a negative attitude about God) on days hospitalized was stronger if the person considered himself more strongly religious. Similarly, Wassel Zavala, Maliski, Kwan, Fink, and Litwin (2009) found that prostate cancer

patients who reported high faith, but did not derive a sense of meaning and peace from their faith reported more pain than the patients who did experience meaning and peace from their faith.

So far, a few studies have investigated the relationship between typologies of S/R and mental health. Riley and colleagues (1998) found, among others, that patients with a chronic illness who were neither religious nor spiritual reported significantly lower vitality and quality of life than only religious or only spiritual patients. Spiritual patients reported the highest levels of vitality and quality of life. Kristeller, Sheets, Johnson, and Frank (2011) found that cancer patients who were neither religious nor spiritual scored lowest on spiritual well-being and quality of life, and highest on depression. Compared to the patients who were both religious and spiritual, the only religious patients reported more negative religious coping, poorer physical, emotional, and functional quality of life, and higher depression. The both religious and spiritual and the only spiritual patients scored similarly on quality of life and depression. However, the results of these two studies are difficult to interpret in terms of causality, because they have used a cross-sectional design and there is conceptual overlap between the measures that were used to identify the types of spirituality – the FACIT-sp (Brady, Peterman, Fitchett, Mo, & Cella, 1999; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002) and the SWBS (Paloutzian & Ellison, 1982) – and the outcome measures (de Jager Meezenbroek, Garssen, van den Berg, van Dierendonck, et al., 2012; Koenig & Larson, 2001).

Nevertheless, there are several reasons to suspect that the four types of S/R differ in mental health. First, evidence is accumulating that experiential aspects of S/R - such as, experiences of connectedness, transcendent experiences, and meaning in life - are more strongly related to mental health than are functional aspects – such as, prayer, church attendance, and religious denomination (Garssen, Visser, & Pool, 2014). Regarding the types of S/R, the people who self-identify as only spiritual seem to be characterized by more spiritual experiences, whereas the only religious are characterized by more religious practices, the both religious and spiritual are characterized by both, and the neither religious nor spiritual have neither (Berghuijs et al., 2013). So, people who consider themselves only spiritual or both spiritual and religious might experience better mental health than the other two groups. On the other hand, several studies have found that both the people who were least committed to religion and who were most committed to religion reported lower depression or higher well-being than those who showed intermediate levels of religious commitment (Eliassen, Taylor, & Lloyd, 2005; Mochon, Norton, & Ariely, 2010; Wei & Liu, 2013), whereas Schnittker (Schnittker, 2001) reported that the least and most religiously committed reported the highest levels of depression. So no clear predictions can be made as to which type of S/R might fare better in the face of cancer.

Second, the four groups might use different coping styles and they might differ in the availability of other coping resources, such as social support and optimism. Various studies have indicated that social support is positively associated with quality of life (Helgeson, 2003; Thoits, 2011) and that the relationship between religion and quality of life

is partially mediated by social support (Idler, 1987; Musick, Koenig, Hays, & Cohen, 1998; Sternthal, Williams, Musick, & Buck, 2010). People who are only religious or both religious and spiritual might experience more social support than people who are only spiritual or neither religious nor spiritual, because religious involvement offers contact with fellow believers. Optimism has also been found to mediate the relationship between spirituality and quality of life (Chan, Rhodes, & Pérez, 2012; Ciarrocchi & Deneke, 2006). Dispositional optimism has been associated with experiential, rather than functional aspects of spirituality (Ciarrocchi, Dy-Liacco, & Deneke, 2008; Mattis, Fontenot, Hatcher-Kay, Grayman, & Beale, 2004), so - given that spiritual rather than religious people seem to be characterized by more spiritual experience - people who consider themselves only spiritual or both spiritual and religious might be more optimistic than those who consider themselves only religious or neither religious nor spiritual. Finally, S/R has been associated with more use of approach-oriented coping strategies than of avoidance coping (Canada et al., 2006; Vespa, Jacobsen, Spazzafumo, & Balducci, 2011). The use of approach-oriented coping styles, such as active coping, positive re-appraisal, and seeking social support, is related to better long-term adjustment to stressful events, compared to the use of avoidance-oriented coping strategies (Taylor & Stanton, 2007). However, it is unclear whether and how the four types of S/R differ in their coping strategies, because the studies investigating the relationship of S/R to coping style have not differentiated between spirituality and religiosity.

In the present study we investigate whether people who consider themselves religious, spiritual, both or neither, differ in their level of adjustment to cancer and whether any such difference can be explained by differences in the coping resources relationship satisfaction, social support, and dispositional optimism, and in coping style. No hypotheses on the specific nature of the differences were formulated. With our study design we have addressed several of the shortcomings of previous studies: (a) We use a longitudinal research design, in order to enhance inferences on the directionality of the relationship between type of S/R and adjustment; (b) we base the typology on the patient's self-identification as a spiritual and/or religious person, in order to reduce the chance of conceptual overlap between the independent and dependent variables; and (c) we explore possible mechanisms for differences between the types of S/R in adjustment to cancer, in order to move toward explanations of the relationship.

Methods

Participants

Participants were recruited from four hospitals and two radiotherapy institutions in the Netherlands, by local members of the medical staff. Patients were eligible for participation if they met the following criteria: They were 18 years of age or older, they were Dutch-speaking, they were treated for cancer with a curative intent, their primary treatment for cancer was surgery or radiotherapy, their treatment had not started more than two months previously, they were not diagnosed with a psychiatric disorder, and they did not have a brain tumor.

During recruitment we attempted to limit a selection bias based on spiritual involvement by urging the members of the medical staff to approach all patients, and certainly not only those patients with an open-mind with respect to spirituality. Also, the information sheet for eligible patients included the following sentences: "Everyone who is treated for cancer is cordially invited to participate in this study. Even if you consider spirituality to be a vague concept or if you feel that's 'not my sort of thing' you can contribute to the study".

Table 7.1 Demographic and medical characteristics of the participants (N = 444)

Age in years (SD)	59 (10.6)
Range	24-83
Gender (%)	
Male	27
Female	73
Having a partner (%)	
Yes	80
No	20
Education (%)	
Low	19
Middle	41
High	40
Member of religious community (%)	
Yes	62
No	38
Religious person? (%)	
Yes	53
No	42
Unsure	5
Spiritual person? (%)	
Yes	50
No	42
Unsure	8
Type of cancer (%)	
Breast	62
Colorectal	18
Gynecological	3
Lung	2
Prostate	12
Other	3

About one-third of the patients who were approached for participation in the study provided written informed consent and filled out the first questionnaire (T1; N = 460). After six months the participants were asked to complete the questionnaires a second time (T2), to which 408 people responded (retention rate = 89%). After another six months, the final assessment took place (T3). This questionnaire was filled out by 383 participants (retention rate compared to T1 = 83%). The main reasons for attrition during the study were death (n = 19), non-response (n = 16), no longer feeling motivated to fill in the questionnaires (n = 22), having developed psychological problems (n = 2), or having become too physically ill (n = 2). In addition, 16 participants were removed from the study, because it was unlikely that they were treated with curative intent. Socio-demographic and medical characteristics of the sample are presented in Table 7.1.

Questionnaires

Adjustment was operationalized as either the presence of well-being or the absence of distress. *Well-being* was assessed with the Joy-in-Life subscale (JiL) of the Health and Disease Inventories (de Bruin & van Dijk, 1996). This is a Dutch questionnaire designed to assess the adaptation to cancer. The JiL showed an internal consistency of α = .82 in a sample of 460 cancer patients (not of the current study). Its convergent and divergent validity were satisfactory: The JiL was negatively related to the distress scales of the Profile of Moods States (POMS) and to the Rotterdam Symptom Checklist, but positively to the Vigor subscale of the POMS. Examples of the items are, "I enjoy the things I do", "I have a good appetite", and "I feel safe" (de Bruin & van Dijk, 1996). In the current sample, the internal consistency of the scale ranged from α = .91 to .92 across the three measurements. *Distress* was measured with the Dutch version of the Hospital Anxiety and Depression Scale (HADS; Spinhoven et al., 1997). This widely used 14-item questionnaire consists of two subscales measuring depression and anxiety, respectively. Previous studies have indicated that spirituality is similarly associated with the two subscales of the HADS and its total score (McCoubrie & Davies, 2006; Noguchi et al., 2004). Therefore, in this study the sum score of the total HADS was used to assess non-specific distress, with higher scores representing more distress. The HADS total score has shown good validity and reliability (Spinhoven et al., 1997). In the current sample the internal consistency ranged from Cronbach's α = .89 to .90 across the three measurements.

Spirituality The *types* of spirituality were determined on the basis of two items that asked participants whether they regarded themselves as a religious or as a spiritual person. Answer categories ranged from 1 "not at all" to 5 "very much", 3 signified "I am in doubt". Persons who scored 1 or 2 on both measures were considered to be neither religious nor spiritual (-R-S). Those who scored 1 or 2 on the spiritual item, but 4 or 5 on the religious item were considered to be only religious (R). Those who scored 4 or 5 on the spiritual item, but 1 or 2 on the religious item were considered to be only spiritual (S). Finally, those who scored 4 or 5 on both items were considered to be both religious and spiritual (R+S). People scoring 3 on either item were discarded from analysis (n = 51). *Religious affiliation* was determined

by asking the participants to which religious community or life-view they felt they belonged. *Non-religious spiritual attitudes, experiences, and practices* were assessed with the Spiritual Attitude and Involvement List (SAIL; de Jager Meezenbroek, Garssen, van den Berg, Tuytel, et al., 2012). This questionnaire consists of six subscales that assess, respectively, the experience of meaning and purpose in life, an attitude of acceptance, an attitude of caring for others, the experience of connectedness with nature, transcendent experiences, and spiritual activities. The SAIL subscale Trust was not used in the current study, because it has shown limited construct validity (Visser, Garssen, & Vingerhoets, 2015). The reliability and validity of the remaining subscales of this questionnaire was demonstrated to be sufficient among five different samples (de Jager Meezenbroek, Garssen, van den Berg, Tuytel, et al., 2012). For the current report we used only the assessment at T1. The internal consistency of the SAIL subscales ranged from Cronbach's α = .73 to .87.

Coping resources The Marital subscale of the Dutch version of the Maudsley Marital Questionnaire (Arrindell, Boelens, & Lambert, 1983) was used to assess *relationship satisfaction*. After consultation with mental health care professionals, we left out 4 items of this 10 item subscale ("How committed are you to this marriage?", "Are you satisfied with the leisure activities that you both share in?", "Does your partner take his/her full share of responsibility?", "Is your partner attractive to you as a person?"), because they might be too confronting in the stressful situation of the diagnosis and treatment of cancer or they might not be applicable due to physical impairments caused by cancer. Furthermore, we adjusted the wording of the questions to the first person (for example, "Do you get enough warmth and understanding from your partner?" became "I get enough warmth and understanding from my partner"), to be answered on a scale from 1 "fully disagree" to 5 "fully agree", to make it fit with the other questionnaires used. In the current study the internal consistency of this 6-item scale was excellent, with Cronbach's α = .88 at T2 and .98 at T1 and T3. *Social support* was measured with an adjusted form of the 6-item Social Support Questionnaire (SSQ6; Pierce, Sarason, & Sarason, 1986). This adjusted questionnaire assesses whether the person feels supported by the people around them on a scale from "almost never" to "almost always", without referring to a specific person as in the original SSQ6. The internal consistency of this scaled ranged from Cronbach's α = .83 to .86 across the three assessments. *Optimism* was measured with the Dutch version of the Life Orientation Test – revised (Fournier, Ridder, & Bensing, 2002). This measure assesses optimistic and pessimistic expectations about outcomes in life. Four items serve as filler items. After reversal of the scores on the three pessimism items, a sum score was calculated over the eight items, with higher scores representing higher optimism. Internal consistency in the current study was good, ranging from Cronbach's α = .78 to .80 across the three assessments.

Coping style was assessed with a 19-item version of the Utrecht Coping List (Schreurs, van de Willige, Brosschot, Tellegen, & Graus, 1993). Although there is some debate on the factor structure of this scale, we have used the five-factor model in the current study (van Rhenen, Schaufeli, van Dijk, & Blonk, 2008). A confirmatory factor analysis on our own

data (N = 460) indicated that this five-factor structure fit the data reasonably well (CFI = .89, RMSEA = .07). The five coping styles assessed are emotional expression, avoidance, seeking social support, active coping, and palliative coping or distraction. The internal consistencies of the scales were acceptable across the three assessments, with Cronbach's α ranging from .68 to .87. Avoidance showed poor internal consistency, with Cronbach's α ranging from .62 to .63 across the three assessments.

Control variables included socio-demographic factors (age, gender, having a partner, having children, the number of children, educational level, having a paid job), medical factors (type of cancer, time since diagnosis, the presence of metastases, still being in treatment at T2 or T3, time since the end of treatment, type of treatment, comorbidity, type of medication used (pain, sleep, anti-anxiety, anti-depressant, other), type of additional care received (pastoral care worker, social worker, psychologist, complementary or alternative care, other), pain, fatigue, and perceived life threat), and the experience of a serious life event other than cancer. *Serious life events* were only assessed at T2 and T3 and were measured by asking participants how often they had experienced a serious life event during the past six months - for example illness other than cancer, a death, relationship problems, financial problems, the birth of a child, marriage, change of address, or retirement - (never, 1 or 2 times, 3 or 4 times, or 5 times or more, respectively). *Pain* was assessed with the pain scale of the Dutch version of the European Organization for Research and Treatment of Cancer, Quality of Life Questionnaire-C30, version 1 (EORTC-QLQ-C30; Aaronson et al., 1993). Participants were asked to rate on a four-point scale, ranging from 1 "not at all" to 4 "very much", how much pain they had experienced during the past two weeks and whether this pain had limited them in their daily activities. In the current study we used the average score of the two items (Fayers, Aaronson, & Bjordal, 1999). Among the cancer patients in the present study the internal consistency of the scale ranged from Cronbach α = .89 to .91 across the three assessments. Fatigue was measured with the Dutch 4-item version of the Checklist Individual Strength (Alberts, Smets, Vercoulen, Garssen, & Bleijenberg, 1997). Participants were asked to rate whether they felt tired, were easily tired, felt well, and felt physically exhausted on a 7-point scale ranging from "Yes, that is true" to "No, that is not true". The item "I feel well" was reverse scored. This shortened version is closely related to the often used, valid and reliable longer version of the Checklist Individual Strength (CIS; Vercoulen et al., 1999). Cronbach's α ranged from .89 at T1 to .90 at T2 and T3. *Perceived life threat* was assessed the Perceived Life Threat Scale (Laubmeier, Zakowski, & Bair, 2004), which was translated into Dutch for this study by AV. This scale consists of 6 items with a Likert type scale ranging from 1 to 6. The internal consistency in the current study was Cronbach's α = .87 to .89 across the three assessments.

Statistical analyses

All analyses were performed using SPSS 19.0 for Windows (IBM Company, 2010). The significance level was set at $\alpha = .05$.

We first investigated whether the four types of S/R reflect different ways of being spiritual, by comparing them on religious affiliation and on non-religious spiritual attitudes, experiences, and practices. Lambda was calculated to test the association between the four types of S/R and religious affiliation. One-way analysis of variance (ANOVA) was performed to examine how the various types of S/R differed at baseline on the subscales of the SAIL, relationship satisfaction, perceived social support, dispositional optimism, and coping style. If the ANOVA indicated that there were significant group differences, Tukey HSD post-hoc tests were used to determine which groups differed from each other.

Hierarchical regression analyses were used to investigate the relationship of the various types of S/R to adjustment. Assumptions of linear regression analysis regarding linearity, multivariate normal distribution, and homoscedasticity were adequately met. The outcome variables were the changes in well-being and distress from T1 to T2 and from T2 to T3. Thus, four regression analyses were performed. The interval from T1 to T3 was not investigated, because curative cancer treatment is usually completed about six months after diagnosis and after this time the patient goes into a phase that is more focused on rehabilitation instead of survival. Consequently, the two time periods may be psychologically and emotionally different, and much information would be lost if they were to be combined into one change score.

In step 1 of each regression analysis the control variables were entered into the model. In order to preserve power, only potential control variables that correlated at $r \geq .20$ with either a dependent or an independent variable were included. These were the medical factors undergoing radiotherapy, using pain medication, using sleep medication, receiving care from a social worker, pain, fatigue, and having experienced a serious life event. In step 2 dummy variables for the types of S/R (R, S, R+S) were added. The -R-S served as the reference group.

If the regression analyses indicated that the types of S/R differed on adjustment to cancer, an additional regression analysis was performed to investigate whether coping resources and/or coping style could explain the group differences. This was done by repeating the regression analysis above and including the coping resources and coping styles as assessed at T1 or T2 in step 2, along with the dummy variables for spirituality. If the effect of the dummy variables is substantially diminished or becomes non-significant, mediation is likely. In accord with the method of Baron and Kenny (1986) for establishing mediation, only the resources and styles that had been found to differ between the groups at baseline in the previous one-way ANOVAs were eligible for inclusion in the regression analysis.

Results

Univariate analyses

Of the 390 participants who were certain about whether or not they considered themselves to be a spiritual or religious person, 28.5% was neither religious nor spiritual (-R-S), 16.9% was only religious (R), 16.2% was only spiritual (S), and 38.4% was both religious and spiritual (R+S).

To check whether the four types of S/R reflected different ways of being spiritual, we investigated group differences in religious affiliation and in non-religious spirituality as measured with the SAIL. There was a significant association between group membership and religious affiliation (see Table 7.2). Inspection of the frequencies suggests that the religious people (R and R+S) were more likely to be affiliated with Roman Catholicism or Protestantism, whereas the non-religious participants (S and -R-S) were most likely to be unaffiliated. In addition, the R+S were more likely than the other groups to be affiliated with another religious community or life view; most often these were other types of Christian movements.

One-way ANOVA indicated that the groups differed on all six subscales of the SAIL (see Table 7.2). Post-hoc tests showed that the participants who were R+S scored higher than those who were -R-S on all aspects of spirituality. The R+S scored higher than the R on Acceptance, Connectedness with Nature, Transcendent Experiences, and Spiritual Activities. The R+S scored higher than the S on Meaningfulness, Acceptance, and Spiritual Activities. The R and S differed only on Transcendent Experiences, with the S scoring higher. The -R-S scored lower than the R on Meaningfulness and Spiritual Activities, whereas they scored lower than the S on Acceptance, Connectedness with Nature, Transcendent Experiences, and Spiritual Activities.

No group differences were found on relationship satisfaction, perceived social support, and dispositional optimism (see Table 7.2). The groups also did not differ in their use of the coping styles emotional expression, avoidance, and palliative coping, but they did differ in their use of seeking social support and active coping (see Table 7.2). Post-hoc tests indicated that both coping styles were used more often by the spiritual participants (S and R+S), than by the non-spiritual participants (R or -R-S). Although the difference on seeking social support between the R and the R+S was not statistically significant.

Table 7.2 Tests of differences between types of spirituality/religiosity on religious affiliation, spirituality, coping resources, and coping styles

	-R-S	R	S	R+S	Effect size	p
Religious affiliation [a]					.27	< .001
None	68	8	78	12		
Roman Catholic	17	41	9	31		
Protestant	11	48	3	37		
Jewish	0	0	0	1		
Islamic	0	0	0	1		
Buddhist	0	0	5	1		
Humanistic	4	0	2	1		
Other	0	3	3	16		
Spirituality [b]						
Meaningfulness	$4.20_{2,4}$	4.50_{1}	4.37_{4}	$4.65_{1,3}$	9.21 [c]	< .001
Acceptance	$4.23_{3,4}$	4.44_{4}	$4.51_{1,4}$	$4.79_{1,2,3}$	14.15 [c]	< .001
Caring for others	4.52_{4}	4.76	4.66	4.88_{1}	7.66 [c]	< .001
Connectedness with Nature	$4.44_{3,4}$	4.60_{4}	4.95_{1}	$4.98_{1,2}$	8.91 [d]	< .001
Transcendent Experiences	$1.80_{3,4}$	$2.11_{3,4}$	$2.74_{1,2}$	$3.01_{1,2}$	38.20 [d]	< .001
Spiritual Activities	$1.76_{2,3,4}$	$2.77_{1,4}$	$2.94_{1,4}$	$4.09_{1,2,3}$	138.06 [c]	< .001
Coping resources [b]						
Relationship satisfaction	26.32	26.00	25.84	26.02	0.15 [e]	.93
Optimism	22.76_{4}	22.94	22.95	23.87_{1}	2.44 [c]	.06
Perceived social support	19.98	20.44	20.57	20.37	0.60 [c]	.62
Coping [b]						
Emotional Expression	4.31	4.21	4.27	4.11	0.72 [c]	.54
Avoidance	6.38	6.48	5.98	6.28	1.24 [f]	.30
Seeking Social Support	$11.68_{3,4}$	11.95_{3}	$13.57_{1,2}$	13.09_{1}	8.44 [d]	< .001
Active Coping	$13.86_{3,4}$	$13.58_{3,4}$	$14.90_{1,2}$	$14.93_{1,2}$	6.75 [c]	< .001
Palliative Coping	9.95	10.21	10.30	9.86	0.87 [c]	.46

Note. The subscripts indicate significant contrasts at $p < .05$; 1 = neither spiritual nor religious (-R-S), 2 = only religious (R), 3 = only spiritual (S), 4 = religious and spiritual (R+S)

[a] Frequencies; The test statistic is Lambda, with Religious affiliation as the dependent variable

[b] One-way ANOVA of means; The test statistic is F

[c] Df = 3, 386; [d] Df = 3, 385; [e] Df = 3, 312; [f] Df = 3, 383

Multivariate analyses

Hierarchical regression analyses were performed to investigate group differences in adjustment to cancer (see Table 7.3). The group variables failed to explain a significant additional amount of variance in the change in well-being or distress at either time interval,

after controlling for the medical variables. Indeed, none of the dummy variables showed a significant effect.

In the interval between T1 and T2, a decrease in well-being was associated with fatigue and the use of sleep medication. An increase in distress during this interval was associated with fatigue and receiving radiotherapy.

In the interval between T2 and T3, an increase in well-being was associated with receiving care from a social worker, whereas a decrease in well-being was associated with fatigue. A decrease in distress during this interval was associated with receiving care from a social worker.

Because the types of S/R did not differ on adjustment, the mediating roles of coping resources and coping styles were not investigated.

Discussion

In the current study we investigated the relationship between spirituality/religiosity (S/R) and adjustment to cancer, by comparing the change in well-being and distress between four types of S/R - neither religious nor spiritual, only religious, only spiritual, or both religious and spiritual - over two 6-month periods after the diagnosis of cancer. Contrary to our expectations, we found no differences in adjustment between the four groups, after controlling for several medical variables. We have also explored possible mechanisms of a relationship between S/R and adjustment to cancer. Again, contrary to our expectations, we found no differences between the groups on relationship satisfaction, social support, and optimism. The participants who were neither religious nor spiritual used the coping styles seeking social support and active coping less often those who were only spiritual or who were both spiritual and religious. The participants who were only religious used seeking social support less often than those who were only spiritual, and used active coping less often than those who were only spiritual or who were both religious and spiritual.

To our knowledge, this is the first study to investigate the relationship between religious and/or spiritual self-identification and adjustment to cancer with a longitudinal research design. Post-hoc power analysis with the program G*power (Faul, Erdfelder, Lang, & Buchner, 2007), indicated that the power of the study to detect a moderate increase in explained variance (f^2 = .075) was .998 with a sample size of 392 (T1-T2) and .996 with a sample size of 366 (T2-T3), given α = .05, 3 tested predictors, and 10 predictors in total. So we feel confident to conclude that these types of S/R do not influence the adjustment to cancer.

A major limitation of the study is that we have only limited knowledge of what it meant to our participants to be religious, spiritual, both, or neither. Similarly to Berghuijs and colleagues (2013), we found that the people who self-identified as only religious or both religious and spiritual were more likely to be religiously affiliated than the other two groups. In addition, the differences on the SAIL between the participants who were both religious and spiritual and those who were only religious confirm that the former endorse both religious and non-religious aspects of S/R, whereas the only religious are more likely to be traditionally

religious. Finally, the differences on the SAIL between the participants who were both religious and spiritual and those who were only spiritual confirm that non-religious spirituality plays a larger role in the lives of the former than of the latter. Thus, there are meaningful differences in the nature and strength of S/R among the four groups.

However, Pargament (2002) indicates that spiritual behaviors, beliefs, attitudes, and experiences are probably most helpful when they fit with each other and with the situation at hand. It is not unlikely that within the four groups of the current study there was great a variety in the level of this integration. This may have obscured an effect of type of S/R on adjustment to cancer. Therefore, our advice for future studies on the effect of different types of S/R on mental health is to take into account the specific content of S/R when forming a typology, instead of only using the person's self-identification as religious and/or spiritual.

In a forthcoming qualitative study among 20 of the participants of the current investigation we have taken first steps in this direction (Uwland-Sikkema, Visser, Garssen, & Westerhof, 2014, 2015). We used a grounded theory approach to form a typology of spirituality and to investigate differences between these types in the adjustment to cancer. The preliminary findings support the suggestion of Pargament (2002) that integration is key and our suggestion that the religious/spiritual self-identification is not specific enough. We discerned four types of S/R based on whether the person indicated that S/R infused his/her whole life or just a part of it, and whether S/R was experienced as transcendent or immanent.

Although one of these four groups consisted of only people who considered themselves neither religious nor spiritual, the other qualitatively derived types could not be distinguished based on the participants' self-identification as religious and/or spiritual. Preliminary findings further suggest that the qualitatively derived types differ in their way of coping with the experience of cancer and in how well their beliefs, attitudes, experiences, and practices fit the experience of cancer. These two factors seem to be related to the degree to which the participants have successfully adjusted to their experience.

Another limitation to consider is the outcome measure that we used. Sawatzky, Ratner, and Chiu (2005) found in their meta-analysis that spirituality was more strongly related to disease-specific measures of quality of life than to generic measures. The meta-analysis of Hackney and Sanders (2003) showed that various types of religiosity were most strongly related to self-actualization. In the current study we have used broad indicators of well-being and non-specific distress that may not fully reflect the pathways by which S/R influences adjustment. The ultimate objective of spirituality is to experience a deep connection with Transcendence (whatever that may be to the person), which gives meaning and purpose to life (Waaijman, 2006). The experience of well-being is only a 'side-effect' of this connection (Belzen, 2004). Therefore, future studies might want to focus on outcomes that are related to this sense of connectedness and meaning/purpose, such as sense of coherence, acceptance, growth, identity reconstruction, or changed goals (Park, 2010).

A third limitation is that the participants were made aware from the beginning that the study was about spirituality, so selection bias based on an interest in spirituality may

Table 7.3 Summary of hierarchical regression analyses of type of spirituality/religiosity on adjustment to cancer.

	T1 – T2 (n = 392)						T2 – T3 (n = 366)				
	Δ R^2, p	B	β	p	95% CI [a]		Δ R^2, p	B	β	p	95% CI [a]
						Well-being					
Step 1	.10, < .001					*Step 1*	.07, < .001				
Sleep medication T2		-2.57	-.11	.03	-4.90; -0.24	Social worker T3		7.91	.19	< .001	3.63; 12.18
Fatigue T2		-0.28	-.26	< .001	-0.41; -0.16	Fatigue T3		-0.17	-.18	.003	-0.28; -0.06
Step 2	.006, .48					*Step 2*	.007, .44				
Sleep medication T2		-2.52	-.11	.04	-4.87; -0.17	Social worker T3		7.86	.19	< .001	3.55; 12.16
Fatigue T2		-0.29	-.27	< .001	-0.41; -0.17	Fatigue T3		-0.17	-.17	.004	-0.28; -0.05
						Distress					
Step 1	.06, .001					*Step 1*	.06, .003				
Radiotherapy T2		1.91	.15	.002	0.70; 3.11	Social worker T3		-5.04	-.20	< .001	-7.65; -2.43
Sleep medication T2		1.56	.10	.05	-0.001; 3.11						
Fatigue T2		0.09	.13	.03	0.01; 0.17						
Step 2	.008, .35					*Step 2*	.004, .64				
Radiotherapy T2		1.88	.15	.002	0.67; 3.08	Social worker T3		-5.01	-.20	< .001	-7.64; -2.38
Fatigue T2		0.10	.14	.02	0.02; 0.18						

Note. Only significant predictors at p < .05 are displayed. Step 1: Radiotherapy, Pain medication, Sleep medication, Social worker, Pain, Fatigue, and Serious life event, as measured at T2 or T3. Step 2: Three dummy variables for the types of spirituality (only religious, only spiritual, religious and spiritual), with the type "neither religious nor spiritual" as the reference group.

[a] 95% confidence interval around B.

have occurred. In terms of religious denomination, our study sample contained somewhat more people who identified as Protestant (27% versus 18%) and less people who identified as 'other' (3.4% versus 10%) than the Dutch general population (Statistics Netherlands, 15-10-2010). In terms of religious/spiritual self-identification, our sample included somewhat less people who considered themselves neither religious nor spiritual (28.5% versus 39.5%) and more people who considered themselves both religious and spiritual (38.4% versus 25.4%) than the Dutch general population (Berghuijs et al., 2013). However, these differences are modest, so they may not have affected the results to a large degree.

Finally, social desirability bias may have played a role in our study, as the majority of the sample scored in the upper ranges on relationship satisfaction and social support. We did not include a measure of social desirability, so we cannot be certain about whether or not this bias occurred. However, taking into account the generally high level of well-being and low level of distress of the participants, it seems to be more likely that our participants are truly well-supported by their partners and friends.

To conclude, whether or not a person considers himself religious and/or spiritual does not seem to affect their adjustment to cancer or the availability of the coping resources relationship satisfaction, social support, and dispositional optimism. When encountering unpleasant situations, people with cancer who consider themselves only spiritual or both religious and spiritual tend to seek social support and use active coping more often than people with cancer who consider themselves only religious or neither religious nor spiritual. For future studies, we advise using a typology of spirituality/religiosity that is based on the degree of integration of spiritual beliefs, attitudes, experiences, and practices, and using disease-specific and meaning- or growth-oriented outcome measures to assess adjustment.

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8.

How spirituality helps cancer patients with the adjustment to their disease[8]

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Abstract

It has been suggested that spirituality is associated with higher well-being, because it offers social support, improves the relationship with the partner, provides meaning, and reduces self-focus and worry. We performed a qualitative study among ten people with cancer, using the Consensual Qualitative Research (CQR) method for the analysis of semi-structured interviews. Support was found for the mechanisms of meaning provision and of reduction of self-focus and worries. Participants also mentioned emotion-focused roles of spirituality: Feeling supported by a transcendental confidant, the expression of negative emotions (in prayer), acceptance, allowing feelings of misery, and viewing problems from a distance. There was no mention of a contribution of spirituality to adjustment through improved social support per se or a higher quality of the relationship with the partner. The results of the present study indicate that the role of spirituality in emotion regulation deserves attention in understanding how spirituality helps cancer patients to adjust to their disease.

Introduction

A diagnosis of a serious disease frequently undermines previously unquestioned trust in reality and can thus provoke a crisis in how the patient has always experienced the meaning of life. One possible pathway for coping with this situation is to turn to personal experiences, feelings, opinions or beliefs that place one's destiny in a larger context, which might imply religiousness for one person and a nonreligious spiritual orientation for another.

Several reviews and meta-analyses have provided evidence for the association between spirituality and well-being (Ano & Vasconcelles, 2005; George, Larson, Koenig, & McCullough, 2000; Hackney & Sanders, 2003; Hill & Pargament, 2003; Koenig & Larson, 2001; Sawatzky, Ratner, & Chiu, 2005; Smith, McCullough, & Poll, 2003; Visser, Garssen, & Vingerhoets, 2010; Yonker, Schnabelrauch, & Dehaan, 2012). Studies have also demonstrated that, compared to people who show less spiritual involvement, patients with a serious disease who attach great value to spirituality show better adjustment, experience a higher level of well-being and quality of life, and experience a lower level of distress (Riley et al., 1998). However, it is less well understood how spirituality might achieve this effect.

One of the first areas that was explored for explanations of the religion - mental health association is the social domain. Church attendance and other organized activities with fellow believers might increase the amount of social support that is received and other relationships might also be of higher quality for religious persons. This was confirmed by Koenig and Larson (2001), who found a relationship between religious involvement and greater social support in virtually all (19 of 20) studies in their review. They explain this finding by suggesting that most religious teachings prescribe support and care for one another. Also, most (35 of 38) studies showed that greater religiousness or similarity in religious backgrounds predicted greater marital happiness or stability.

James and Wells (2003) have developed a cognitive-behavioral framework to explain how religion may affect mental health. They propose two mechanisms: religion as a generic mental model and self-regulation opportunities offered by religion. The first mechanism signifies that religious beliefs guide the appraisal of life events. A religious belief system enables individuals to find meaning in stressful life events that are otherwise difficult to explain. This would help to maintain a sense of control and predictability of the world. Other studies have confirmed that belief systems play a beneficial role in coping with physical illness by providing a new meaning to a disease (Blow et al., 2011).

The self-regulation mechanism proposes that religious beliefs and activities direct the current of thought and attention. For example, the belief that certain thoughts are sinful can help a person to reduce these thoughts. Also, meditative prayer suspends worry or rumination. In the words of Baetz and Toews (2009): "Religious behaviors that contribute to self-regulation by reducing self-focus and worry while producing a calming effect (for example, contemplative prayer, mindfulness, meditation, and religious rites) are positively associated with mental health." (p. 294).

The cognitive-behavioral framework of James and Wells largely corresponds to the concept of religious coping (Pargament et al., 1999; Thuné-Boyle, Stygall, Keshtgar, & Newman, 2006). There are two forms of coping: primary and secondary coping. Primary coping refers to efforts to change the situation, such as praying for divine intervention. Secondary coping refers to efforts to change the self in order to adapt to the situation, such as reframing the perceived meaning of a situation as a reflection of God's will (comparable to the generic mental model of James and Wells) or undertaking religious activities that influence emotional distress, for example meditation, contemplative prayer and rituals (comparable to the self-regulation mechanisms of James and Wells).

Our current study concerns the role of spirituality in the adjustment to cancer. In our view, spirituality overlaps with religiosity, so the mechanisms described above might also be able to explain the effect of spirituality on psychological well-being.

A main theme in definitions of spirituality is connectedness (Chiu, Emblen, van Hofwegen, Sawatzky, & Meyerhoff, 2004; Dyson, Cobb, & Forman, 1997): connectedness with oneself, connectedness with the outer world, and connectedness with the transcendent. Reed (1992) defined spirituality on the basis of conceptual, empirical, and clinical nursing literature as "the propensity to make meaning through a sense of relatedness to dimensions that transcend the self in such a way that it empowers and does not devalue the individual. This relatedness can be experienced intrapersonally (as a connectedness within oneself), interpersonally (in the context of others and the natural environment) and transpersonally (referring to a sense of relatedness to the unseen, God, or power greater than the self and ordinary source)." (p. 350). The dimension Connectedness with Oneself is expressed by aspects such as authenticity, inner harmony/inner peace, consciousness, self-knowledge, and experiencing meaning in life. Connectedness with the Outer World is expressed by aspects such as compassion, caring for others, gratitude, and wonder. Connectedness with the Transcendent includes awe, sacredness, and connectedness with something or someone beyond the human level, such as the universe, transcendent reality, a higher power, or God (Chiu et al., 2004; Elkins, Hedstrom, Hughes, Leaf, & Saunders, 1988; Howden, 1992; Hungelmann, KenkelRossi, Klassen, & Stollenwerk, 1985; Mahoney & Graci, 1999).

To summarize, theories and previous quantitative studies have suggested that spirituality/religiosity increases psychological well-being by enhancing the availability of social support, improving the relationship with one's partner, offering a sense of meaning, controllability and predictability to life events, and reducing self-focus and worry while producing a feeling of calmness. However, most of the studies on these mechanisms were quantitative in nature, which means that the presuppositions of the researchers for the most part determined which mechanisms would be studied. It begs the question whether these are the only pathways through which spirituality influences the adjustment to cancer. In addition, these quantitative studies provide information on whether or not the mechanisms exists, but they do not describe how these pathways might operate in real life. Therefore, it seems imperative to systematically analyze how cancer patients themselves describe the

ways in which spirituality has helped them to adjust to the consequences of their disease. Such an analysis may also yield suggestions for additional mechanisms that have not been included in previous theories. To this end we have interviewed cancer patients and qualitatively analyzed these interviews.

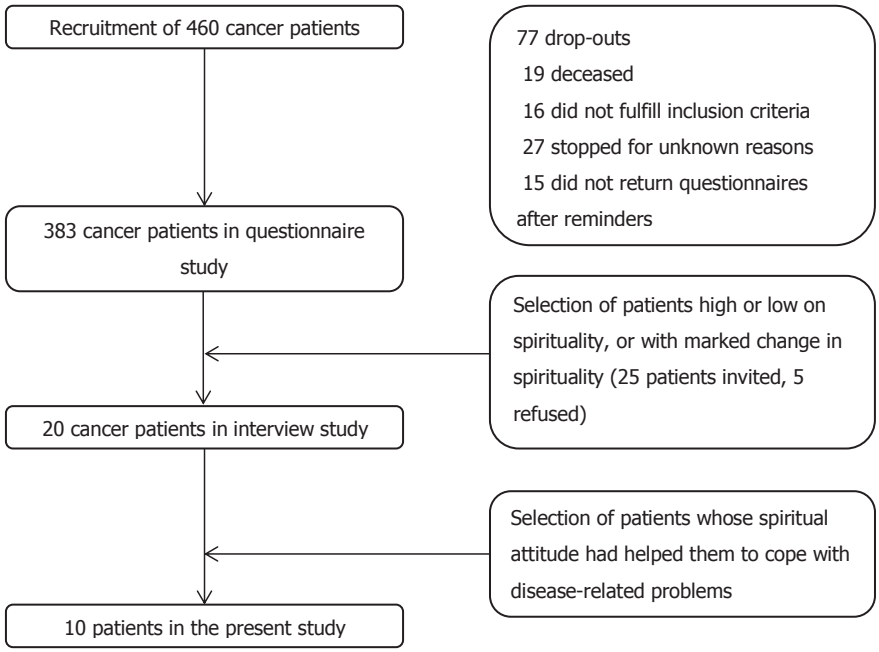
Methods

Participants

This interview study is part of a larger quantitative and longitudinal study into the role of spirituality in the adjustment of cancer patients. Participants in that study were recruited in four hospitals and two radiotherapy institutions. Eligible patients met the following inclusion criteria: born in the Netherlands, Dutch-speaking, receiving curative cancer treatment, and having a life-expectancy of one year or longer. All cancer types were included except brain tumor. Patients with psychiatric disorders were also excluded. The patients were approached by a member of the medical staff shortly before or after surgery, or at the start of radiotherapy. After having sent the signed informed consent form to the researchers, the participants completed the first questionnaires (T1). On the informed consent form participants could indicate if they wanted to be interviewed one year later (T3). All participants received a gift certificate of 7.50 Euros with the first questionnaire. Participants who were interviewed received an additional gift certificate of 10 Euros.

At the final measurement moment potential interviewees were selected through purposive sampling, with the intent to maximize the variance in spirituality and well-being among the interviewees. This would allow us to understand more clearly whether spirituality provided something unique to the process of adjustment to the experience of cancer. A profile was made based on the quantitative data they had provided throughout the study, which included the scores on a spirituality questionnaire (the Spiritual Attitude and Involvement List; de Jager Meezenbroek et al., 2012), and scores on a well-being questionnaire (the Health and Disease Inventories subscale Joy in Life; de Bruin, van Dijk, & Duivenvoorden, 1996) and distress questionnaire (the Hospital Anxiety and Depression Scale; Spinhoven et al., 1997). If a profile stood out - for example, the person scored high on spirituality but low on well-being/high on distress, or showed a marked change in spirituality or well-being/distress – the person was selected to be interviewed. ‘High or low’ meant scoring in the highest or lowest sextile. When a participant was selected based on his/her profile, the researcher (NU) called the person by telephone to inform whether the participant was still willing to be interviewed, to provide any additional information he/she might need and to schedule an appointment.

Figure 8.1 Recruitment and selection of the participants in the present study



Interviews

Semi-structured interviews were designed to elicit a narrative on the relationship between the person's life view and the experience of cancer. The interviewee was first invited to describe how he/she had experienced the past year, from the time of diagnosis to the moment of the interview. Next, the interviewee was asked more specifically about her or his life view. In the last part of the interview the person's definition of spirituality/religiousness and its role in coping with the disease were discussed explicitly. The participant was not offered a standard definition of spirituality.

Interviews lasted about 2 hours (1 to 2¾ hours) and were held at the participant's home. All participants were interviewed by the same person (NU), who is a trained and experienced interviewer. Interviewing for the present study was started after three successful pilot interviews. All interviews were recorded on a digital memo recorder and verbally transcribed. To check the interviewer's understanding of the participant's story a summary of the interview was sent to the interviewee for comments. All participants confirmed its accuracy.

Analysis

The 20 interviews were evaluated by three independent raters (NU, BG & AV) with respect to several questions that were designed to obtain a consensual rating of the level of well-

being and spirituality of the interviewee. For the present study we focused on the question "To what degree has the spiritual attitude of the participant helped him/her to cope well with disease-related problems". This was scored on a five-point scale ranging from "clearly helped" to "spirituality is unrelated to coping with disease-related problems, or could not find any indication that spirituality was helpful". In case of a difference in scores the interview was discussed among the three raters until agreement was reached. The ten patients who had received a score of 3 or higher - that is, patients who showed indications that their spirituality had helped them to cope with problems related to cancer - were selected for further analysis.

To uncover the various ways in which aspects of spirituality might affect the process of adjustment to the consequences of cancer, the interviews have been analyzed with the Consensual Qualitative Research (CQR) method, introduced by Hill, Thompson and Williams (Hill et al., 2005; Hill, Thompson, & Williams, 1997). The essential component of CQR is the independent evaluation of semi-structured interviews by several judges, who in the present study were the three authors. The judges discuss their evaluations to arrive at a consensual opinion about the meaning and categorization of the data. This evaluation takes place in four phases: definition of the domain of study (i.e. the research questions), selection of interview fragments, description of core ideas, and categorization of core ideas. One element of the CQR method that we did not apply is the use of an auditor, a specialist in the field, who examines the consensus versions of the categorizations and presents his or her comments to the judges, who discuss these comments to again reach consensus. We decided not to use an auditor as the judges in the present study are experienced in the field of spirituality research and include one senior researcher (BG) and one researcher with an education in qualitative research (NU). In their update of CQR, Hill et al. (2005) designate the use of an auditor only as an optional addition to their method.

In the present study there was only one domain, namely 'spirituality of cancer patients in relationship to their adjustment to disease-related problems'. Interview fragments that represented this domain were selected by mutual agreement. Next, each of the three judges tried to capture the essence of the fragment in a few sentences, which are called 'core ideas'. These core ideas were discussed among the judges until agreement was reached about the content and wording of the core ideas. Then, each judge summarized the core ideas into categories that reflected the spiritual adjustment process. These categories were also discussed until agreement was reached. In case new categories were formulated as a result of the discussions among the judges, the step of classifying core ideas under categories was repeated. Examples of core ideas are 'I can leave my troubles with someone when being in church and praying' and 'Meditation has helped me to cope well with life during the cancer period'. These core ideas fall under the following categories, which are presented here as examples: 'Being in church', 'Praying' and 'Meditation, contemplation and yoga'.

After this qualitative analysis according to the CQR method, we have tried to describe the processes by which the aspects of spirituality bring about positive mental states in terms of general psychological concepts. This helps to relate our findings to the theoretical

mechanisms of the effect of spirituality on adjustment that are mentioned in the literature. We realize that such a translation only mirrors the spiritual content, but does not totally cover it. For instance, we suggest that praying and telling your sorrows to a relative have a psychological process in common, namely emotional expression, although praying also includes the acknowledgement and experience of a transcendental being that is greater than any human being. For this final phase in the examination of our results, we will also use the

Table 8.1 Characteristics of the study group, also in comparison to the characteristics of the total sample

	Interview group N=10	Total sample N=383
Gender - male	10%	26%
Mean age (years)	52	58
Partner	90%	80%
Children	90%	81%
Children in household	80%	30%
Education		
low	0%	15%
middle	70%	42%
high	30%	42%
Working outdoors	90%	52%
Denomination		
Roman Catholic	40%	24%
Protestant	30%	27%
Otherwise	0%	10%
None	30%	39%
Do you consider yourself…		
Spiritual and religious	50%	34%
Spiritual, not religious	40%	15%
Religious, not spiritual	10%	15%
Not spiritual, not religious	0%	36%
Type of cancer		
Breast cancer	70%	65%
Prostate cancer	10%	12%
Cervix cancer	20%	3%
Other types of cancer	0%	20%
Metastases at T1*	40%	19%

two global mechanisms described by James and Wells (2003), which we have discussed in the Introduction.[9]

Qualitative research often suffers from a lack of credibility (reliability) and transparency. We have applied the CQR method, because it contributes to the objectivity of the findings. We acknowledge that our interpretation of the findings is to some degree speculative. However, it is indispensable, if one wishes to go beyond the mere description of what has been said by interviewees, toward explaining these experiences and forming a theory to enable generalization and further testing of the results. Only then can we speak of having conducted qualitative research (Sandelowski, 1996).

Results

The characteristics of the study group are presented in Table 8.1. Our sample included only one man. The mean age of the participants was 52 years. All but one participant had a partner and all but two had children living at home. For the current study, only those interviewees were selected of whom the researchers believed their spirituality had contributed to their coping with cancer. This selective sampling is reflected in the fact that all participants considered themselves spiritual; only one person considered himself religious but not spiritual. Three persons said not to belong to any religious denomination. Most participants had breast cancer, which reflects the high rate of breast cancer among the female population.

We found 59 interview fragments in which an interviewee spoke about an effect of spirituality on adjustment. The number of fragments per person varied from 1 to 14, with a mean of 6. Using the CQR analysis, the 59 fragments were subsumed under fourteen categories. These are presented in Table 8.2 and described below, including the interpretation of these fourteen categories. The interpretations are summarized further in Figure 8.2. For the sake of convenience we have grouped the fourteen categories in three larger domains: 'Spiritual experiences or convictions' (A), 'Spiritual activities' (B) and 'Spirituality – General' (C).

Spiritual Experiences and Convictions

A1. Viewing the disease as a task (to learn a personal lesson or to mean something to other people). This category included many fragments: 10 out of the 59 fragments, which were derived from six of the ten interviews. Especially religious people considered cancer as a task, coming from God:

I think you've also learned to belief that this [the cancer] gives meaning to your life… . That it crossed your path and that you didn't choose this, but that you can choose how to deal with this. That it's a kind of task of yours. Of how you deal with the things that cross your

9 We read the article of James and Wells (2003) after having finished the CQR procedures. So, the selection of fragments and the categorization of these fragments were not influenced by previous knowledge of the pathways in their theoretical framework.

path. So I think it's a challenge to view that [the cancer] positively and optimistically. And to carry out that message.

Interpretation: In the coping literature, this way of thinking is labeled 'reframing' or 'positive reinterpretation'. Conceiving of cancer as a task makes the illness meaningful, because it has 'come across your path' to learn from, deepen your belief or pay more attention to the important things in life. It thus fits into the first mechanism of James and Wells.

A2. The experience of, or a belief in a personally interested and supportive God. This category includes most fragments: 18 out of the 59 fragments, though they were derived from only four of the ten interviews. The interviewees described how God helped them by listening and comforting:

> I think that I was much less preoccupied with anxiety …. Sometimes, I found it dead scary, terribly tense, but I have someone to whom I can hold. I am a Christian for more than thirty years now and He has never let me down. Why would he do that now?"
>
> "Once I discussed it [the disease] with someone, who said 'I would be quite nervous if I were you. Why aren't you?' Well, to be honest, I sometimes lie awake at night, but God is always awake. Then I think we are awake together, and then I can pray, pray for all those people who come to my mind. Because I was no longer preoccupied

Figure 8.2 Suggested psychological mechanisms that might explain how spirituality helps patients to adjust to their disease

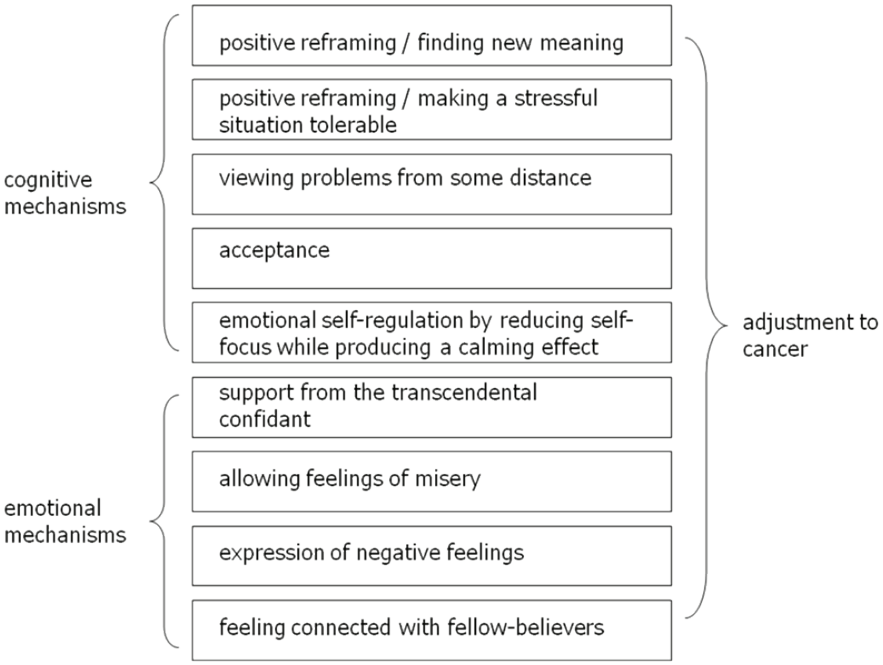


Table 8.2 The processes through which spirituality can help in the adjustment to cancer; categories arising from the analysis of interviews with ten cancer patients

Spiritual category	No. of fragments *	No. of participants **	Suggested psychosocial processes
A1. Viewing cancer as a task	10	6	Positive reframing
A2. Experiencing a personally interested and helping God	18	4	Support from the transcendental confidant
A3. Belief in an afterlife	4	3	Positive reframing
A4. Conviction that death is part of life	2	1	Acceptance
A5. Fellow believers being engaged in spiritual activities on behalf of the patient	2	2	Feeling connected with fellow believers
A6. Experience of light	2	1	Allowing feelings of fear and misery
A7. Receiving a spiritual message	5	2	Positive reframing such that the situation becomes tolerable
B1. Praying	5	4	Expression of negative emotions Viewing problems from some distance Reducing self-focus and worry while producing a calming effect
B2. Being in church	2	1	Reducing self-focus and worry while producing a calming effect
B3. Meditation, contemplation, yoga	7	3	Viewing problems from some distance Reducing self-focus and worry while producing a calming effect Acceptance
B4. Putting situations in the light	2	1	Positive reframing such that the situation becomes tolerable
B5. Contact with spiritual care provider	2	2	Feeling connectedness with fellow-believers Support from the transcendental confidant Positive reframing
C1. Spirituality – general	2	2	NA
C2. Spirituality did not help	3	3	NA

* The sum of this column is larger than the total of 59 interview fragments, as some fragments fell into more than one category

** Number of participants whose interview fragments fell into a particular category

A. Experiences or convictions

B. Activities

C. General

> with myself but with those other people and because I was engaged with God, I became so calm that I fell asleep again.

The interviewees rarely indicated that they asked God to cure them from cancer. The relation with God was seen as a collaborative one; one has to take action oneself, but God will help when asked to do so. Though God is not always seen as directing one's life, he decides about life and death: "He could just as well have plucked me out of it, He would then say 'You, come to me, it has been enough' (…) but he allows me more life."

Interpretation: This category seems to refer to the image of a father who listens to your problems, and offers support and comfort. This 'Father-in-Heaven' is asked for emotional support and - only in rare cases - for instrumental help. Some interviewees described His emotional support in physical terms, similarly to what an ideal human father would do: "God will catch me when I fall and dry my tears when I cry" or "When I feel anxious or desperate, he will hold his arms under me". This conviction gives certainty, trust and inner strength, similarly to the effects of knowing that a human father will always help and support you. Without being disrespectful, one might suggest that the positive effects of the experience of and the belief in a personally interested and helping God is in line with the positive effects of having one or more confidants here on earth. We have, therefore, attached the label 'support from the transcendental confidant' to this category.

A3. Belief in an afterlife. Persons who mentioned a 'Belief in an afterlife' often indicated that such a belief makes present problems less important and reduces a fear of death:

> Everything works out, even if I hear 'your life will only last another three months'. Then it is also all right, you know, because if you have a living faith in the Lord Jesus you know you have an eternal life.

Only one person had a non-religious view of an afterlife: "Even if I would die from cancer, I still wouldn't be afraid of it, because then you take off this coat and you go on – that's how I see it – you go from one dimension into another one."

Interpretation: For the persons interviewed for this study, the 'belief in an afterlife' subdued a fear of death. The conviction that one is prepared for a better life during the present life will also put current problems in a milder perspective. It is certainly not identical, but seems comparable to the coping style of 'seeing things in a positive light'. In a situation that is rather burdensome, it helps to look forward to a brighter and lighter future. This category also fits into the first idea from James and Wells of religious beliefs guiding appraisals of life events – in this case impending death – enabling individuals to find meaning in stressful life events that are otherwise difficult to explain.

A4. Conviction that death is part of life. Fragments from one interview fell into this category. The participant said: "I won't live to a hundred years, I think. So yes, I think about that just very realistically, I mean, the second time [that she was diagnosed with cancer] I had the strong feeling of 'O, this was it' and I just felt it is a part of life".

Interpretation: This conviction might seem related to the previous one, but this notion implies the acceptance of the fact that one's personal life will come to an end, whereas belief in an afterlife implies the continuation of one's life in another form. The truism that one's life will end is, of course, in itself not spiritual. Instead, to be aware of the finiteness of one's personal life and to integrate this awareness into one's thinking is considered spiritual.

A5. Fellow believers being engaged in spiritual activities on behalf of the person. This category includes citations such as:

> So, I also received postcards with 'Well, we will pray for you' and 'We will pray that our prayers go with you into the operating room'. Well, I kept those thoughts with me…. That surgeon drew very precisely how she would do all that. And then I said to her, do you know that people will be praying for you? ….. Yes, you pray for yourself and you are not dependent on their prayers, but it gives extra courage, like doing an exam and everybody is thinking of you.

Interpretation: The knowledge that 'fellow believers are engaged in the same spiritual activities' led to a feeling of connectedness with other people, which supported the patient's emotionally when they had to endure unpleasant medical procedures.

A6. Experience of light. One participant described an 'Experience of light' that came after an episode of somberness and desolation. This experience resulted into her letting go of the fear of death and the (wish to have) control over life and death.

> In that period, I have been anesthetized three times in a short period. And each time I had nightmares for a week…. I would wake up panicky with sweating and trembling. I couldn't move and was absolutely sure I would die at that moment. Then I heard two weeks after surgery that the cutting surfaces were not totally clean and that I needed radiotherapy. 'Till that moment I had the feeling I was totally in control and was prepared for anything…. This I had not foreseen. And somehow, in the midst of that misery, in that terribly dark gloom I thought 'yes that might be, but I am still alive and now I can make the choice: or I can go with the gloom and become a very sad woman, or I can think 'Hey, I am still alive'….That was a kind of, just a little stream of water with light in it.

Interpretation: One might guess that this experience involves a process of allowing feelings of fear and misery, ultimately leading to a sense of acceptance and relief. Allowing feelings of fear and misery can be compared to the flooding procedure in behavioral therapy.

A7. Spiritual message received. This message could come from the personally involved and helping God. Whereas prayer implies that the person actively contacts God, the spiritual message is experienced as having been sent from the outside:

> But really, panic struck me. I thought to myself 'I have to go anyway', and went with trembling legs to that X-ray department. …. It was really difficult; it literally seized me by the throat. I was so upset that I could not even swallow a sip of water. Then I was waiting in that cabin, all on my own. And I was thinking 'Oh, what if it is wrong again?' Suddenly there was: 'You have searched me, LORD, and you know me,

> Psalm 139'.… It was there simply and suddenly and I thanked God for that, because I didn't have it in me at that moment. But He gave that to me then …. You know it completely. If it is good. You already know. If it is wrong, You know it already.
>
> The message could also be non-religious and come from a human being:
>
> About a week before I would receive the first chemotherapy, I was extremely anxious then…. I was outside cleaning my windows (…) and then the neighbor from across the street walked up to me and said to me: … 'Yes, man suffers most from the suffering he fears'. Oh, then I really felt that she was sent to me. I needed to hear that, because, indeed, I was driving myself crazy with something that was not at all happening yet.

Interpretation: The participants described having received a message that was strikingly appropriate for the situation they were in. This spontaneity and relevance might have contributed to their belief that the message had been sent by the transcendent. The message fit into ('triggered') the spiritual beliefs of the person. From the examples given, one cannot conclude that this re-appraisal of threatening situations lead to experiencing the situations as meaningful, but rather as tolerable.

Spiritual Activities

B1. Praying. The relation with the helping God was experienced during prayer: "Yes, I pray about what is troubling me, or about problems I have no answer for at that moment; that you can leave your problems with someone." Sometimes, prayer did not have the character of presenting specific problems to God, but more of being in His trustful presence:

> I mean, you could lie awake in your bed for hours, but if I then – this might sound very stupid – for instance if I just spent some time in bed praying then I notice I become quite peaceful. I could have taken a sleeping pill, but that is quite unnecessary then. That trust, and then falling asleep, that is wonderful, yes.

Asking God for direct interference in one's life was viewed as appropriate by some, but inappropriate by others: "Yes indeed, we have asked in prayer whether God would cure me" or "It is actually praying what I do, the Lord's prayer and such, but not 'Please let it happen that my daughter stops using drugs'".

Interpretation: Praying seems comparable to the 'emotional expression' of negative feelings and thoughts to a confidant. Though praying might involve more than telling one's misery to God, such as worshipping or asking for advice, these other themes were not mentioned in the interviews. Instead, patients said for instance: "By praying I could get rid of my troubles". Telling one's problems to God or to another person has two potentially positive consequences. First, one will receive sympathy and comfort. Second, personal problems are 'externalized'. Telling your sorrows to the transcendental confidant creates some distance from one's troubles, also because they are seen through His eyes. Viewing problems from some distance will lessen their impact and will free one's mind for considering cognitive or behavioral adjustments.

Only once did an interviewee describe her prayer in a different form: “When I am lying awake at night, I sometimes say a well-known prayer. It gives me the trust of ‘it will turn out well’ and I fall asleep quietly”. This seems comparable to saying a mantra, and seems different from emotional expression. This form of ‘calming’ prayer thus seems to fit into the second mechanism from James and Wells of a spiritual activity implying self-regulation by reducing self-focus and worry while producing a calming effect.

B2. Being in church. One participant said she went to church to be in a serene, peaceful environment, and to be in contact with God: “I didn’t even go to church more often, but at the moments I was there it did me a lot of good. Just the silence, to repent and also to trust you’re on the right path”.

Interpretation: People might go to a church for different reasons: Because of the comforting and serene environment, to meet God, to speak to the chaplain or priest, or because they like to be with fellow believers. This category applied to one person who indicated that being in church brought calmness and comfort, and that in church she could leave her worries with someone. One might conclude that going to church had the self-regulatory effect of reducing self-focus and worry while producing a calming effect.

B3. Meditation, contemplation and yoga. Some participants deliberately undertook activities such as meditation, yoga, or contemplation to calm down, to create some distance from their situation, or to cope with physical problems: ”Spirituality is in the moments of calmness or reflection (…) to list all the points in your head, to relax and just be with yourself for a while”.

> I was really knocked out for a week. Then I was just lying in the bedroom waiting for it to be over (…), terribly sick (…), then I would do a kind of Yoga exercises, just breathing and thinking ‘it is what it is, it will pass’ (…) that helped me to get through.

Interpretation: These categories are all activities aimed at quieting inner turmoil and promoting inner rest. It thus fits into the idea from James and Wells of a self-regulation mechanism. Meditation and contemplation can also involve looking at what is happening in one’s life in a non-judgmental way and from some distance.

B4. Placing situations in the light. This was described by one participant. It implied visualizing a bright light on a situation, which she learned in a spiritual group.

> I did a training some years ago mainly about working with light, light around you, to attract the positive. How can I explain? …. For instance, I had to have an injection in my uterus or something like that, the day before surgery. They said ‘You will have a very unpleasant injection, it will hurt gigantically and apologies in advance’. …. I did that exercise and the doctor asked ‘don’t you feel anything?’ No ‘We are already finished. Haven’t you felt anything, how is that possible?’

Interpretation: This activity implied imagining an ideal situation when in trouble and believing that this will ’attract’ good things. It can also be interpreted as another example of spirituality guiding the appraisal of a stressful situation such that it became more tolerable.

B5. Contact with a spiritual care provider. The fragments suggested that the negative psychological effects of the disease and its treatment were reduced, because a spiritual care provider could relate to the transcendental framework of the patients' view on the event. The care provider was a pastor for one person and a spiritual healer for another person:

> I know about the ways of many things in my head, but I could never feel it well. …. So, I had made an appointment with that lady to help me with that. …. And I saw her, which was – there is no such thing as coincidence – on the morning that I was diagnosed, though our appointment was made two months earlier. So we felt it was meant to be. And then she gave me the healing. I have to say it was very special, because you feel all kinds of things, tingling and energy waves, whereas I could not feel anything before. The funny thing is, I stepped outside and the whole world seemed brighter and more intense, the light was different, and as if the birds sang louder.

Interpretation: The contact could imply several of the working mechanisms mentioned before, such as stimulating the experience of/belief in a personally interested and helping God, or the experience that fellow believers are engaged in the same spiritual activities, dependent on the activities of the priest or healer.

Spirituality – General

These remaining two categories did not refer to any specific working mechanism.

C1. Spirituality – General. In some fragments the interviewees spoke of their spirituality in general having been helpful, such as "If I hadn't had my faith during this period, or just had not had it anyhow, I would not have known how to deal with it. It has supported me tremendously".

C2. Spirituality did not help. Though our selection procedure implied that every participant spoke of the helpful role of spirituality, some fragments indicated that this was not always the case:

> I am religious and then you think to yourself 'He let me down'. Is there a special meaning in it, or something? (…) At a certain moment, I was also very sad and angry because of how other people live their lives; they live from one day to the next; they eat unhealthy and so on. You think to yourself 'Why me?' (…) I have also spoken with the reverend, who visited me here at home before I started with chemotherapy. And he said 'He [God] is not responsible [for getting cancer] (…) and I hadn't understood.

Discussion

The aim of the present study was to understand how spirituality helps cancer patients to cope with their disease. To that end, we have interviewed patients and have selected ten interviews that – according to independent raters – showed a supporting role of spirituality. The qualitative analysis of these ten interviews yielded several spiritual attitudes, behaviors or processes that aided the patients in their adjustment to cancer, which could be subsumed under fourteen categories.

Several of our categories fitted into existing concepts (See also Figure 8.2). The interview categories 'Viewing cancer as a task' and 'Belief in afterlife' gave support to the idea of James and Wells (2003), that spirituality guides appraisals of life events by enabling individuals to find new meanings in stressful life events that are otherwise difficult to explain. The categories 'Receiving a spiritual message' and 'Putting situations in the light' indicate a different type of re-appraisal in which a situation is not explained, but re-evaluated in a brighter, more positive way. We have distinguished two other cognitive mechanisms, which can be labeled as re-appraisals but are not mentioned by James and Well, namely 'Viewing problems from some distance' and 'Acceptance'. Viewing problems from some distance can be an element of 'Praying'. 'Conviction that death is part of life' implies Acceptance, which can also be part of 'Meditation etc.'.

The second cognitive process described by James and Wells, the self-regulation mechanism, applied to our categories 'Praying', 'Being in church' and 'Meditation etc.'.

We have ascertained several spiritual mechanisms not mentioned by James and Wells. Emotion-focused mechanisms, which James and Wells explicitly did not take into account, appeared important in our interviews. Examples are 'Experiencing a personally interested and helping God' and 'Praying'. Both categories can be summarized under the heading 'Support from the transcendental confidant'. Our participants might have found new meaningful interpretations of their present situation in their contact with God, but the prominent feature was the emotional component of receiving comfort from a God who listens. Our characterization of Experiencing a personally interested and helping God and of Praying is – of course – not original and can, for instance, be found in the description of the 'Relationship with God' of Gall and Cornblat (2002), and of 'Prayers for comfort' of Levine, Aviv, Yoo, Ewing, & Au (2009). The emotional element could also be seen in the suggested psychological mechanisms of 'Allowing feelings of misery' and 'Expression of negative emotions' (in prayers).

In developing the RCOPE, Pargament, Koenig, and Perez (2000) distinguished five religious functions in coping: (1) to give meaning to an event, (2) to achieve a sense of mastery and control over difficult situations, (3) to provide comfort during times of difficulty, (4) to provide intimacy with other likeminded people, and (5) to assist people in making major life transformations. Three functions - 1, 3 and 4 - can be easily recognized in our categories. Function 2 of Pargament et al. is represented by items such as "Worked together with God as partners" and "Prayed for a miracle". Items like the first one fit in with our category

Experiencing a personally interested and helping God. Activities represented in items like the second one - “Prayed for a miracle” - were not mentioned by our participants. None of our participants spoke about a life transformation induced by the disease as suggested by the fifth function, be it that for some participants their spiritual attitude was intensified. Altogether, most of the functions distinguished by Pargament et al. can also be found in our categories.

Qualitative studies are not suited to exclude possible explanations, but are used to find new possible hypotheses. Yet, it is remarkable that none of the participants mentioned that they had experienced social support through church attendance and other organized activities with fellow believers. Going to church was done for other reasons; finding peace and comfort, and contact with God. Contact with fellow believers was mentioned, but the helpful aspect was ‘Feeling connected because fellow believers engage in spiritual activities on behalf of the patient’, not social support in general.

The small number of participants and the use of a selective sample could be considered drawbacks of our study. However, these characteristics are inherent to a qualitative study. Our study is purposely based on a selective sample: We included only cancer patients who scored at least moderately high on a spirituality questionnaire and whose interviews – according to three independent raters – showed that spirituality has at least to some degree helped in coping with cancer-related problems. It is evident that the findings of the present study mainly reflect the viewpoints of women. Only one man (10%) was included in the sample of the present study, which was mainly due to the composition of the total sample of which only 26% was male.

The outcome of a qualitative study will partly depend on the viewpoints of the researchers themselves with respect to the research question. The Consensual Qualitative Research (CQR) method offers some protection against a biased position, because several evaluators independently judge the material, followed by a discussion of possible differences and the formulation of a consensual opinion. Though all three researchers are interested in spirituality, one is a religious person, one an agnostic and one an atheist, which gives some guarantee against a biased position. The definition of spirituality that was used in this study was rather broad, as described in the Introduction.

A recurring point of discussion was whether a citation described an effect of spirituality or not. For example, the fragment ‘I trust that everything will turn out all right’ raised a discussion, because we have considered ‘Trust’ as an aspect of spirituality (de Jager Meezenbroek et al., 2012), but the word is also often used in common language with a non-spiritual intent. If the interviewee had not presented additional information, the fragment was rejected as not reflecting a role of spirituality. This was also done when the trust of the person was based on his or her previous experiences of being capable of dealing with difficult situations. However, if the trust implied a role of God who is expected to put one’s life on the right trail, or if a person accepts his or her fate whatever it brings, the fragment was accepted as reflecting a role of spirituality.

On the basis of theory and interpretation of our own data we arrived at the following themes that can explain the effect of spirituality on adjustment to cancer-related problems: (1) appraisals of disease-related events, enabling individuals to find meaning in stressful life events that are otherwise difficult to explain, (2) appraisals of disease-related events presenting a new meaning to one's suffering that makes a threatening situation tolerable, (3) viewing problems from some distance, (4) acceptance, (5) emotional self-regulation by reducing self-focus and worry while producing a calming effect, (6) support from the transcendental confidant, (7) allowing feelings of misery, leading to relieve, (8) expression of negative feelings (in prayers), and (8) feeling connected with fellow believers. Several of these themes concern cognitive mechanisms (categories 1-5), but there is also an important emotional component in spirituality (categories 6-9). Spirituality thus offers people with cancer several ways to deal with meaning(lessness) and with the greater problems in life.

The aim of the present study was to unravel the spiritual mechanisms that help people in their adjustment to the disease. What clinicians might learn from this study is that patients use a diversity of spiritual sources. This includes the often mentioned process of finding meaning, but also the direct comfort and the certainty of being heard in prayers. Certain spiritual behaviors also help people to express negative feelings and to place problems at some distance, which makes these problems more manageable, and spiritual behaviors may create silence and peace of mind. If problems seem overwhelming some people may turn to the 'Confidant in Heaven', while other people follow the more solitary path of allowing feelings of misery. Professionals in spiritual care should have an open mind for this variety of spiritual coping mechanisms.

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9

Discussion

This dissertation on the role of spirituality in the psychological adjustment to cancer was written with two aims in mind. The first aim was to investigate the conceptual overlap between spirituality and well-being, in order to get a better understanding of what spirituality is and to provide guidance to future research on the relationship between these two concepts. The second aim was to investigate the relationship between spirituality and psychological adjustment to cancer, in order to better understand what the directionality of this relationship is, which aspects of spirituality might be of main importance to adjustment, and what the mechanisms might be that underlie a relationship between spirituality and adjustment.

In this chapter I will first summarize the main findings of this dissertation. Then I will discuss the strengths and limitations of our investigation. Based on these sections I will present some recommendations for future research. Finally, I will close this chapter by summarizing the main conclusions of this dissertation.

Main findings

Part 1. Defining spirituality

In *chapter 1* I began this dissertation by outlining how spirituality may be defined. Based on a brief overview of the literature I concluded that spirituality and religion are related, but independent constructs. Religion refers to an organized system of beliefs, practices, rituals, and symbols, whereas spirituality is defined as "one's striving for and experience of connectedness with the essence of life" (de Jager Meezenbroek et al., 2012, p. 142). Religion and spirituality meet when this striving takes place within the context of an organized religion. Religion and spirituality diverge when a person feels affiliated with a religion without striving for connectedness with the essence of life or when a person strives for connectedness with the essence of life outside of a religion. One problem with the definition of spirituality is, however, that the essence of life can be found in any aspect of life, which makes it difficult to determine where spirituality ends and psychological concepts such as 'well-being' begin.

In *chapter 2* we encountered this conceptual problem again, when I reviewed 40 studies that had been published up to the year 2009, on the relationship between well-being and non-religious spirituality or meaning in life among people with cancer. I found that 59% of the studies on spirituality had used the FACIT-sp (Brady et al., 1999) as a measure of spirituality. This questionnaire assesses spiritual well-being, which is a dimension of quality of life, and shows large content overlap with the outcome measures used. Of the studies on meaning in life, 23% had used the Meaning in Life Scale (Jim, Purnell, Richardson, Goden-Kreutz, & Andersen, 2006), which also contains several items referring to aspects of well-being. In addition, 90% of the studies had used a cross-sectional design, precluding conclusions on directionality. These methodological problems led me to conclude that we still know very little about the nature of the relationship between non-religious spirituality and well-being among people with cancer.

To ensure that we were not making the same conceptual mistake as previous studies had and to help future researchers in this field to overcome the problem of conceptual overlap, I have investigated in *chapter 3* whether the measure of spirituality that we used in our own research (the Spiritual Attitude and Involvement List, or SAIL; de Jager Meezenbroek et al., 2012) overlaps with the measure of well-being that we used (the Joy in Life scale; de Bruin & van Dijk, 1996). We were especially interested in the SAIL subscales Meaningfulness, Trust, and Acceptance, because they measure concepts that are also often included in the definition of spiritual well-being. We concluded that the SAIL subscale Trust showed overlap with the Joy in Life scale. The other subscales of the SAIL did seem to measure aspects of spirituality.

Of course, the SAIL is not the only existing questionnaire on spirituality. Therefore, in *chapter 4,* my colleagues and I examined the item content of nine other spiritual well-being/ spirituality questionnaires to establish their degree of overlap with well-being. We found that both the short (6 items) and long (15 or 16 items) versions of the DSES (Underwood & Teresi, 2002), the FACIT-sp (Brady, Peterman, Fitchett, Mo, & Cella, 1999), the Rush Religious/Spiritual Struggle Screening protocol (Fitchett & Risk, 2009), the SIWB (Daaleman & Frey, 2004), the SWBS (Ellison, 1983), and the WHOQOL-SRPB (WHOQOL SRPB Group, 2006) contained a problematic proportion of items that directly referred to well-being or that referred to a positive relationship between spirituality and well-being. The psychometric properties of the Jarel Spiritual Well-being Scale (Hungelmann, Kenkel-Rossi, Klassen, & Stollenwerk, 1996) have been insufficiently demonstrated (Monod et al., 2011; Sessanna, Finnell, Underhill, Chang, & Peng, 2011), so for future studies on the (causal) relationship between non-religious spirituality and well-being we recommended the use of either the SAIL without the subscale Trust, or the SWBQ (Gomez & Fisher, 2003), also known as the SHALOM (Fisher, 2008).

Part 2. Spirituality and adjustment to cancer

In *chapter 1* I had indicated that the prevalence of cancer is substantial and that it can lead to high economic costs, partly because of the emotional burden of this disease. A review of the literature showed that 12% to 30% of people with cancer experience chronically or increasingly poor mental health during and after the treatment of cancer. Regarding the other 70% to 88% of patients, spirituality might contribute to the ability to maintain or regain mental health, and I proposed several mechanisms that might explain why spirituality can be a source of resilience: social support, optimism, and approach-oriented coping (particularly, positive reappraisal).

In *chapter 5* my colleagues and I examined the evidence about the directionality of the relationship between spirituality and mental health in various populations, by reviewing 47 longitudinal direct effects studies and 26 moderation studies. We concluded that there is limited evidence for a causal effect of spirituality on mental health. The large variation in populations, sample sizes, aspects of spirituality, and measurement methods used in the studies is likely responsible for this lack of effect. Religious guidance was most consistently

found to be directly and indirectly related to mental health, but the only two studies that had used a scale of proven reliability and validity to measure this factor did not find an effect. Only three longitudinal studies and none of the moderation studies had included cancer patients and virtually all of the reviewed studies had assessed religious spirituality.

Therefore, in *chapter 6* I investigated the moderation effect of non-religious spirituality on the adjustment to cancer-related stressors in a cross-sectional and a longitudinal study. I found a moderation effect of spirituality in the longitudinal study, but not in the cross-sectional study: During the first six months after the start of cancer treatment, meaningfulness seemed to reduce the negative effect of fatigue on distress. During the following six months acceptance and spiritual activities seemed to reduce the negative effect of fatigue on distress. In addition, acceptance seemed to reduce the negative effect of perceived life threat on distress, whereas caring for others seemed to strengthen this negative effect. A direct relationship between spirituality and mental health was observed in the cross-sectional study, but not in the longitudinal study: All aspects of spirituality except spiritual activities were positively related to well-being, whereas only meaningfulness and acceptance were negatively related to distress.

In *chapter* 7 I reexamined the prospective direct effect of spirituality on adjustment to cancer. However, instead of using the SAIL as a measure of spirituality as we had done in chapter 6, I operationalized spirituality as the participant's self-identification as either religious, spiritual, both, or neither. I found that the participants who considered themselves only spiritual or both religious and spiritual were more inclined to use the approach-oriented coping styles of active coping and seeking social support, but the groups did not differ on adjustment to cancer.

The fact that we found so little evidence for a relationship between spirituality and adjustment to cancer made us question our choice of measures for both concepts. Therefore, in *chapter 8*, my colleagues and I investigated in a qualitative study among 10 highly spiritual people with cancer how they described the contribution of their spirituality to coping with the experience of cancer. We found that the spiritual experiences of a personally interested and helping God, spiritual support from fellow believers, light, and receiving a spiritual message; the spiritual beliefs of viewing the cancer as part of a task, the existence of an afterlife, and viewing death as a part of life; and the spiritual practices of visiting a church, prayer, meditation, contemplation, yoga, and visiting a spiritual care provider had been helpful when coping with cancer. The participants described that these aspects of spirituality had a positive effect on both cognitive factors – positive reframing, taking some distance from the problem, acceptance, and self-regulation of worry and self-focus – and emotional factors – feeling supported by the Transcendent, allowing feelings of misery, being able to express negative feelings, and feeling connected with fellow believers.

Strengths and limitations

The research reported on in chapters 3, 6, 7, and 8 of this dissertation has some notable strengths, because it was conducted in response to several limitations of previous research (see Chapter 1). Nevertheless, it also has its shortcomings. Here I will discuss the main strengths and limitations with regard to the study sample, the study procedure, and the measurement of both spirituality and adjustment to cancer.

Sample

One strength of the current study is its large sample size and high retention rate. The large sample size (N = 383) resulted in very high statistical power, so we can be quite confident about our results. In addition, the high retention rate (83%) reduces the chance of sample bias due to selective loss to follow up. However, the participants who were lost to follow-up had reported more pain and fatigue at baseline (see Chapter 3). Therefore, we do need to take into account that the conclusions apply mainly to people who experienced fewer physical symptoms at the beginning of cancer treatment. In addition, the majority of the sample (62%) was diagnosed with breast cancer, whereas in 2010 (the year most participants were recruited) the incidence of breast cancer made up only 9% of the total cancer incidence of that year (Comprehensive Cancer Centre, 2-11-2014). Consequently, our findings are not representative of the entire population of people receiving curative treatment for cancer, but are mainly representative of women with breast cancer.

Another strength of the sample is that there was no selection bias on the level of spirituality. The distribution of religious affiliations of our sample was comparable to that of the Dutch general population, although our sample contained somewhat more people who self-identified as Protestant (27% versus 18%) and less people who self-identified as 'other' (3% versus 10%; Statistics Netherlands, 15-10-2010). The distribution of people who self-identified as religious, spiritual, both, or neither was also quite comparable to that of the Dutch general population, even though our sample contained slightly more people who self-identified as both religious and spiritual (39% versus 25%) and less people who self-identified as neither religious, nor spiritual (29% versus 40%; Berghuijs, Pieper, & Bakker, 2013a). So it seems that our results are reasonably representative for both non-spiritual and highly spiritual people with cancer, and both religiously spiritual and non-religiously spiritual people with cancer.

Procedure

In terms of the study procedure, two strengths of our study are that (a) it focused on the most stressful period within the cancer trajectory (the first year after the diagnosis of cancer), when spirituality might be most helpful, and (b) that it had a longitudinal research design, which provides more information on the directionality of the relationship between spirituality and adjustment to cancer. On the other hand, the assessments were as much as six months apart and by the second assessment already 60% of the sample had completed active cancer

treatment. Henselmans, Coyne, Sanderman, de Vries, & Ranchor (2009) found among women with breast cancer that distress was highest during moments of transition: shortly after diagnosis (on average 12 days after diagnosis), shortly after surgery (on average 1.7 months after diagnosis), at the end of adjuvant treatment (on average 5.6 months after diagnosis), and two months after the end of adjuvant treatment (on average 7.2 months after diagnosis). Gall and colleagues (2009) found that religious coping was used most often one week before surgery, though it remained quite stable during the following two years. The participants in our qualitative study also often indicated that their spirituality had been most helpful to them when awaiting the diagnosis and when preparing for surgery or chemotherapy (see Chapter 8). Given that our first quantitative assessment took place on average three months after the diagnosis of cancer, when many patients had already undergone surgery, and our second assessment took place six months later, we have probably missed the major transitory moments at which spirituality might have had its greatest impact on psychological adjustment.

Operationalizations

Throughout this dissertation I have made clear that spirituality is a complex concept that is difficult to separate from other psychological constructs. In this regard, a strength of our investigation is that the definition and operationalization of spirituality reflect the current line of thinking about what spirituality entails and that we explicitly studied the conceptual overlap between our measures of spirituality and well-being in order to avoid tautological conclusions. We have also paid attention to both religious and non-religious spirituality. This means that the results from this study can be generalized to a wide variety of types of spirituality.

On the other hand, it seems that we may have missed the aspects of spirituality that are most important for the adjustment to cancer. Especially the belief that the occurrence of cancer was part of a greater task in life, the experience of a God who cares about the person and wants to help him/her, and the practice of prayer were considered to be helpful by the participants (see Chapter 8). In chapter 5 we found that experiencing religious guidance was most likely to be causally related to mental health, either directly and/or indirectly by reducing the negative effect of stressors. However, the SAIL contains only two items that refer to such aspects: Within the subscale Spiritual Activities there is one item that reads “There is a God or higher power in my life that gives me direction”, and one item that asks whether the person meditates or prays, or takes time in some other way to attain inner peace. Spiritual activities did reduce the negative effect of increased fatigue on distress between 6 and 12 months after the start of treatment, but we found no direct relationship between spiritual activities and adjustment (see Chapter 6).

We also may have used inappropriate outcome measures, because the participants indicated that aspects of spirituality were especially helpful in terms of emotion regulation and positive reappraisal or meaning-making coping (see Chapter 8). Some definitions of

spirituality already contain references to its outcomes. For example, Tanyi (2002) indicates that spirituality brings faith, hope, peace, and empowerment. Reed (1992) suggests that spirituality empowers the person and that it leads to authenticity, inner harmony or peace, self-knowledge, the experience of meaning in life, compassion, gratitude, and wonder. Park (2010) proposes that meaning making – an important function of spirituality – results in a sense of coherence, acceptance, growth, identity reconstruction, or changed goals. For sure, if the main characteristic of spirituality is to strive for and experience connectedness with the essence of life, it seems obvious that spirituality primarily affects concepts that refer to the attainment of connectedness, and that it perhaps only indirectly affects mood-related outcomes such as well-being or distress.

In addition to this methodological shortcoming, there is also an important theoretical issue to consider: Perhaps there is no causal relationship between spirituality and adjustment to cancer. Perhaps spirituality and well-being/distress are two sides of the same coin; either because they are both consequences of a third factor such as personality or because they are two aspects of an overarching concept, much like physical and social well-being are both aspects of quality of life. After all, we found that at a cross-sectional level most aspects of spirituality were directly related to well-being (though not distress), whereas we found little evidence for a longitudinal relationship between spirituality and well-being or distress (see Chapters 6 and 7). In chapter 2 I also indicated that, despite the methodological shortcomings of the reviewed studies, there is more support for a cross-sectional relationship between spirituality and mental health than for a longitudinal relationship. Finally, the participants mostly described the mood-related effects of spirituality as being instantaneous (see Chapter 8).

On the other hand, most aspects of spirituality seem to represent an independent domain (see Chapter 3) and I have explored only a few possible explanations for why spirituality and well-being are related. One possibility I have not investigated is that spirituality and well-being are united by the experience of meaning and purpose in life. As I will discuss further below, our finding that Meaningfulness was associated similarly with the other aspects of spirituality as with well-being (see Chapter 3) seems to point in that direction.

Then again, why do we focus so much research attention on the relationship between spirituality and mental health? Even though I had indicated in chapter 1 that I hoped that this dissertation would aid care professionals in helping people with cancer to adjust to their experience, it is not our task as social scientists or (mental) health care professionals to intervene in the spirituality of a person. Instead, if we feel from a psychological or medical point of view that unmet spiritual needs or spiritual concerns interfere with the person's health, we need to refer the person to a pastoral care worker or a spiritual counselor who has a better understanding of the spiritual healthiness of the person's struggles.

There are several reasons why I write these cautionairy words. First, because we do not have the training to intervene in the spirituality of a person in a professional manner. Second, because we do not have the specialized knowledge to determine whether or not any

consequences of spirituality are unhealthy (Belzen, 2004). Many spiritual traditions teach that negative experiences and emotions can lead to great spiritual growth, for example in the case of an existential crisis or "dark night of the soul" (St. John of the Cross, 1578/1579). This is also what we found in chapter 8. Also, what is considered unhealthy is very much determined by the culture in which one lives (Belzen, 2004; Moberg, 2002). Furthermore, the attainment of mental health is not the objective of spirituality. As Waaijman (2006) describes, spirituality is a relational process between God and man. Both God and the person are identified in terms of this relationship or unity: God [10] (hereafter referred to as 'transcendence') is the whole to which the person relates and the person is that which is in relation with the whole. The person is made complete and mature through his/her relationship to transcendence. So the ultimate objective of spirituality is to attain this unity between man and transcendence, which gives meaning and direction to life. Although within most types of spirituality the awareness and experience of unity are accompanied by physical, psychological, social, and spiritual health, or peace, these consequences are considered to be a by-product of spirituality (Belzen, 2004).

Of course, I'm not trying to say here that the vast amount of research conducted on the relationship between spirituality and (mental) health should be discarded and that my hard work on this dissertation is completely pointless. It is our job as psychologists (and social scientists in general) to describe, explain, and predict human behavior, and spirituality is an aspect of human behavior. In addition, spirituality has a legitimate place within care for people with cancer, or any other person for that matter. Tronto (1993) defines caring as "a species activity that includes everything that we do to maintain, continue, and repair our 'world' so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web." (p. 103). As we have seen throughout this dissertation, the world of a spiritual person is shaped by his/her relation with transcendence. So in order to maintain, continue and repair the world of spiritual people with cancer, we need to understand their spirituality, how this spirituality affects their understanding and experience of the occurrence of cancer in their lives, and what it means to them to 'live as well as possible'. We should, however, ensure that we leave spirituality in its own right and that we do not reduce it into a means to an end that is not its own, and that we operate within the boundaries of our professions (Belzen, 2004; Pargament, Magyar-Russell, & Murray-Swank, 2005).

Future research

Although the main purpose of this dissertation was to investigate the role of spirituality in the adjustment to cancer, I have devoted much attention to the difficulties of research on spirituality. These difficulties seem to be far from solved, because spirituality is an ineffable

10 To avoid confusion with a traditionally religious conception of God, I will refer to it as 'transcendence' from here on, with the explicit understanding that this does not only refer to a force or power that is higher than the person, but also to something broader than the person that is shared with other people or nature, or to something deeper within the person.

part of life, which we probably can never fully capture with any type of measurement instrument (Moberg, 2002). However, for research on the consequences of spirituality to move forward, we need to find a way to get past this hurdle. Therefore, I want to address two measurement issues here that seem to be particularly important for future research on the relationship between spirituality and human functioning: The positions of meaning and purpose in life and of spiritual beliefs within the definition and the assessment of spirituality.

Meaning and purpose in life

One question that seems particularly pertinent regarding the definition and the measurement of spirituality is whether or not these should include the experience of meaning and purpose in life. In the framework that I have used in this dissertation, this experience is an integral part of spirituality. However, several findings suggest that the experience of meaning and purpose in life is an outcome of spirituality, and that including it in the definition of spirituality may bias the association between spirituality and mental health. First, definitions of spirituality present it as the *search* for meaning, with the *experience* of meaning as its outcome. Second, the experience of meaning and purpose in life is considered to be an aspect of existential well-being (Edmondson, Park, Blank, Fenster, & Mills, 2008; Ledbetter et al., 1991; MacDonald, 2000; Mazzotti, Mazzuca, Sebastiani, Scoppola, & Marchetti, 2011; Paloutzian & Ellison, 1982), which in turn is an aspect of quality of life (Brady et al., 1999; Fisher, 2011; WHOQOL SRPB Group, 2006). Third, meaning-related concepts are related to well-being to a similar degree as to other aspects of spirituality (see Chapter 3; Migdal & MacDonald, 2013). Fourth, the presence of meaning in life acts as a (partial) mediator between spirituality and life-satisfaction (Hicks & King, 2008; Krok, 2014; Steger & Frazier, 2005; Steger, 2012), though not emotional functioning (Holt, Oster, Clay, Urmie, & Fouad, 2011).

On the other hand, it might be argued that both the search for and the experience of meaning and purpose in life should be included in definitions of spirituality, because spiritual beliefs and experiences provide a unique view of oneself, one's life, and the world, as related to transcendence (MacDonald, 2009; Pargament et al., 2005; Park, 2007). The studies I discussed above – including my own – have assessed a general sense of meaning and purpose to life, that can be derived from spirituality, but also from other sources, such as the person's family life, occupation, sports, or political views (Hicks & King, 2008; Park, 2010). This may explain why the construct was found to take a mediational position in the relationship between spirituality and mental health, instead of belonging to spirituality. Further research is needed to understand to what extent spirituality provides a special type of meaning and purpose in life, and how the search for and experience of such *spiritual* meaning affect the person's mental health.

Such future research will need to take into account that searching for and experiencing meaning in life may be differentially related to mental health (Steger et al., 2010; Steger, Kashdan, Sullivan, & Lorentz, 2008) and that some types of spirituality may be more conducive to the search for meaning and purpose, whereas others may be more conducive

to the presence of meaning and purpose in life (Martos, Thege, & Steger, 2010; Steger et al., 2010). For example, people who consider themselves only spiritual are characterized by openness to experience and place high value on spiritual transformation, which implies a greater inclination toward searching for meaning and purpose; whereas people who considered themselves only religious score lower on openness to experience and place high value on orthodoxy or traditionalism, which implies that they already experience meaning and purpose in life (Berghuijs et al., 2013a; Saroglou, 2010; Saucier & Skrzypinska, 2006).

Beliefs

Another issue that requires further investigation is the inclusion of spiritual beliefs within the assessment of spirituality. Many instruments assess various religious or paranormal beliefs, such as a belief in God, in an afterlife, or in spirits or ghosts, but this reduces the applicability of these instruments to certain types of spirituality. The SAIL does not assess beliefs – apart from one item within the subscale Spiritual Activities that reads: "There is a God or higher power in my life that gives me direction" – which makes it applicable to a wider range of types of spirituality. However, the exclusion of beliefs makes it difficult to determine whether what is being assessed is unique to spirituality. As many have argued, what distinguishes spirituality from other psychological concepts is the awareness of and relation to transcendence (Belzen, 2004; Kapuscinski & Masters, 2010; Pargament et al., 2005; Waaijman, 2006). So if we want to determine whether or not a person is spiritual, it seems imperative that we assess beliefs about the existence of a transcendence to which the person relates and which motivates his/her actions.

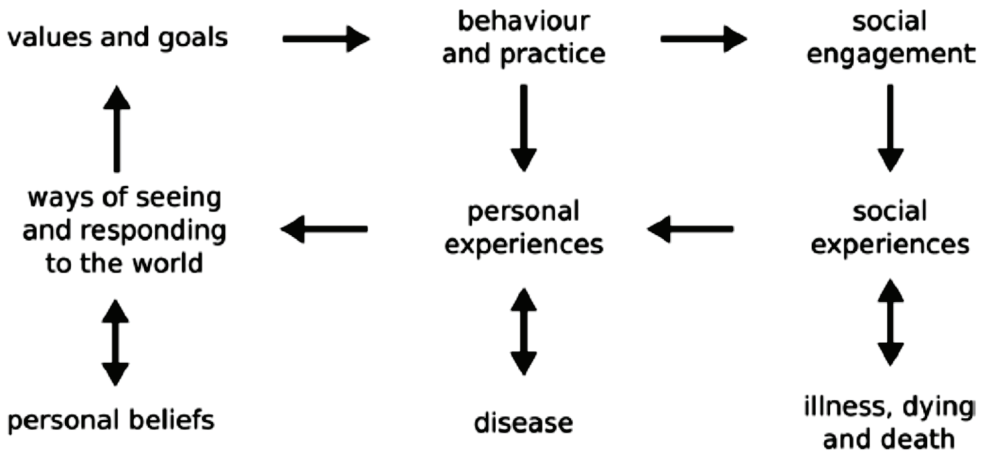
The assessment of spiritual beliefs might not only be important to define the boundaries of spirituality, but also to explain potential differences in mental health between people with various types of spirituality. Spirituality acts as a meaning system, which influences how a person interprets events in his/her life and how the person will respond to these events (James & Wells, 2003; Park, 2007; Schnittker, 2001). A person experiences distress when life events violate some of the most central beliefs, values, norms, or goals of the meaning system (Jeserich, 2014; Pargament et al., 2005; Park, 2010).

On the other hand, measuring spiritual beliefs is not an easy feat. Directly asking people about their beliefs about and relationship to transcendence seems unwise, because the word 'transcendence' is very abstract and many people might not be able to relate this to their own beliefs and experiences. In addition, giving concrete examples of transcendence seems impossible, because beliefs are influenced by the sociocultural background and previous experiences of the person, and people blend and select elements from various spiritual traditions to fit their lives, leading to an almost infinite variety of meaning systems (Berghuijs, Pieper, & Bakker, 2013b; Moberg, 2002; Molzahn et al., 2012; Park, 2005; Saucier & Skrzypinska, 2006). What's more, there may not be a clear set of aspects of spirituality that are of importance to most people in a certain situation, because the history of a person

will determine under which circumstance which aspect of spirituality is relevant for mental health (Pargament, 2002).

To find a solution to this problem, Moberg (2002) and Pargament (2005) recommend using a particularistic approach toward spirituality, which means investigating specific kinds of spirituality among specific people dealing with specific situations in specific social contexts, and to apply comparative analyses to the results. This will provide more information on which aspects of spirituality affect people's lives in what ways, and whether or not there is a subset that is especially important for positive or negative functioning, that may even be shared among various types of spirituality. The danger of this approach is, however, that it will lead to fragmented research efforts that investigate each element of spirituality in isolation, whilst they are likely to interact in their effects on mental health. Therefore, strong theoretical frameworks are needed to lend coherence to this body of research. One promising framework has recently been developed by Cobb, Dowrick, and Lloyd-Williams (2012) in the context of palliative care. In their synoptic model, Cobb and colleagues present aspects and consequences of spirituality as related to the individual, the social context, and cultural or societal factors (see Figure 9.1). A model like this can help researchers to put their own studies in perspective and can remind them of which aspects of spirituality or possible consequences are not yet understood. In addition, the reciprocal nature of the pathways in the model can act as a reminder that spirituality is not static, but that it is affected by experiences and circumstances.

Figure 9.1. Synoptic model of spirituality. From "Understanding spirituality: a synoptic view" by M. Cobb, C. Dowrick, and M. Lloyd–Williams, 2012, BMJ Supportive & Palliative Care, 2, p. 340. Copyright 2012 by BMJ Publishing Group ltd.. Reprinted with permission.



Methodological considerations

The conceptual and methodological difficulties that I have described above have several consequences for how future research on spirituality should be conducted. Because we need to stand upon the shoulders of giants if we want to see further (Isaac Newton), I base most of my recommendations on those by Moberg (2002) and MacDonald (2011).

1. If we want to gain a better understanding of the nature of spirituality, comparative and interdisciplinary research seems imperative. By comparing different types of spirituality we can get a better grasp of the universal characteristics of this multifaceted phenomenon, but at the same time remain aware of the differences. Psychologists studying spirituality should be aware and make use of the knowledge already gathered within, for example, comparative religious studies, theology, cross-cultural psychology, anthropology, and sociology. We do not need to reinvent the wheel when it comes to understanding what spirituality is, we just need to place it in a different perspective: that of the individual experience.
2. When studying this individual experience we need to use a variety of research methods that complement each other; not just quantitative, self-report questionnaires, but also qualitative interviews, ethnographic research, and more objective measures (such as the frequency of engagement in spiritual practices). This will enhance our ability to capture various aspects, interpretations, manifestations, and consequences of spirituality.
3. When choosing a self-report scale, we need to reflect explicitly on (a) which aspects of spirituality it does and does not capture, (b) whether or not it reflects a certain type of spirituality (religious or non-religious, Christian, Buddhist, New Age, paranormal, etc.), (c) whether or not it assesses spiritual well-being or mental health, (d) whether or not it can distinguish between spiritual and non-spiritual people, and (e) what its psychometric properties are. In other words, we should be aware of and make explicit where our research is positioned within the differentiated body of research, so that it becomes easier to build theoretical frameworks.
4. Given the multitude of spirituality scales already available, some of which have quite good theoretical and psychometric foundations, we should only construct new scales if there are sound theoretical and empirical arguments as to why existing scales do not suffice for the research question at hand. If a scale does not yet exist for the particular type of spirituality under study, we should consider adapting an existing instrument, so that there is a theoretical and empirical basis on which to build. The use of supplementary questions to a universal measure should also be considered, so that findings from different types of spirituality can more easily be compared and contrasted. Instruments that might be suitable as a starting point are the aforementioned SAIL without the subscale Trust (de Jager Meezenbroek et al., 2012) and SWBQ/SHALOM (Fisher, 2008; Gomez & Fisher, 2003), but also the more religiously oriented Expressions of Spirituality Inventory without the EWB subscale (MacDonald, 2000; MacDonald, 1997).

5. When investigating the role of spirituality in the adjustment to cancer, we should use multiple measurement moments at clinically relevant times. In a curative setting this might include moments such as, shortly before the diagnosis, between reception of the diagnosis and the start of treatment, shortly after surgery, at the beginning of adjuvant treatment, at the end of adjuvant treatment, before check-ups, and shortly after the diagnosis of cancer recurrence. This will enhance our ability to understand the role that spirituality plays in coping with highly stressful situations. In addition, we should investigate outcomes and mechanisms that more closely reflect the core of spirituality: meaning, purpose, and connectedness. There are a multitude of psychological concepts that are relevant to these aspects, such as meaning-making coping, sense of coherence, benefit finding, post-traumatic growth, self-actualization, appraisal, goal-adjustment, spiritual struggle, social support, spiritual support, mastery, sense of control, harmony, self-esteem, peace, forgiveness, gratitude, and spiritual well-being. Given the specific demands that cancer places on a person we should also pay more attention to disease-specific outcomes.

Conclusion

Regarding the definition of spirituality, we can conclude that the essence of spirituality is the relatedness that a person seeks and experiences with transcendence. Further research is needed to distinguish spirituality more clearly from its consequences. Trust and existential well-being are likely to be consequences of spirituality, but it is as of yet unclear what the positions of the search for and experience of meaning and purpose in life are within spirituality.

Regarding the role of spirituality in the adjustment to cancer, the functional elements of spirituality seem to be the belief in and experience of spiritual guidance, the experience of spiritual support, the practice of prayer, and the attitude of acceptance. Future research should include multiple measurements at clinically relevant times with mixed research methods. In addition, future research should use outcome measures that are disease-specific and that fit better with the goal of spirituality. Theoretical frameworks are needed to organize this vast body of research.

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Appendix

Supplementary tables Chapter 5

Table A.1 Summary of studies on the prospective direct effect of spirituality on mental health

Author(s)	Sample characteristics	N	Interval	Predictors [a]	Sufficient control [b]	Outcome variables	Findings	Comment	Decision
Barton et al., 2013	adult offspring of women at low and high risk of depression; mean age 29 years; USA	173	10 years	church attendance	yes	diagnosis of major depression	no effect		
Bekke-Hansen et al., 2014	acute coronary syndrome patients; mean age 61 years; Denmark	85	6 months	belief in God, belief in spiritual power, religious coping	yes	depression (subscale of PHQ-9)	no effect	the effect of religious coping was ignored, because one of the two items concerned spiritual well-being	
Bosworth et al., 2003	depressive patients; age ≥ 60 years (mean 67 years); USA	78-90	6 months	public, private religious activities, positive religious coping	yes	depression (MADRS)	effect positive religious coping	1/3 tests significant	limited effect

(Table A.1 continued)

Braam et al., 1997	population sample; age range 55-89 years; The Netherlands	A. 129 B. 48	1 year	religious salience	no	A. incidence B. chronicity of depression (CES-D≥16)	effect on chronicity, but only among females and persons with poor physical health (pain, chronic diseases and functional limitations)	4/9 tests significant; correction for baseline depression was indirect through differentiation between incidence (implying no depression at baseline) and chronicity (implying depression at baseline)	limited effect
Braam et al., 2007 (Same study group as Braam et al., 2004)	population sample; age 55-85 years (mean age 74 years); The Netherlands	1346	3 years	prayer	yes	depression (CES-D)	no effect		

(Table A.1 cont.)

Chan et al., 2012	female students who survived the hurricanes Katrina and Rita; mean age 25 years; USA	386	median: 14 months	composite measure (church attendance and importance of religion)	yes	distress (combination of K6 and PSS4)	no effect		
Chen et al., 2007	elderly primary care patients with depression or anxiety disorders; ≥ 65 years (mean age 74 years); USA	1073	6 months	religious participation (daily, weekly, monthly or less, never)	yes	depression (CES-D)	effect of weekly and monthly or less participation, compared to never	daily participation may be considered a somewhat obsessive behavior	effect
Dew et al., 2010	adolescent psychiatric patients; mean age 14 years; USA	104	6 months	private religious practices, positive religious coping, positive and negative religious support, commitment, organizational	yes	depression (BDI)	no effect		

(Table A.1 cont.)

				religiousness, meaning, self-ranking					
Ellison et al., 2008; same databank and same data points as Ellison & Flannely, 2009	population sample of adult African Americans; mean age 50 years	645	3 years	church attendance, religious guidance, support from church members	yes	distress (RAND MHI)	effect of religious guidance and attending church more than once a week compared to monthly attendance	2/3 tests significant	effect
Ellison & Flannelly, 2009; same databank as Levin & Taylor, but different T1	population sample of adult African Americans; mean age 50 years	607	3 years	church attendance, religious guidance, support from church members	yes	major depression (NIMHI interview)	effect of religious guidance	1/3 test significant	limited effect

(Table A.1 cont.)

Fitchett et al., 1999	rehabilitation patients; mean age 65 years; USA	96	T1: before discharge from hospital T2: 4 months later	church attendance, religiousness (composite measure), positive religious coping, acceptance/ meaningfulness	no	depression (BDS), satisfaction with life (SLS)	no effect		
Gall et al., 2009	breast cancer patients; mean age 61 years; Canada	92	T1: before biopsy T2: 6 months post-surgery T3: 1 year post-surgery	religious salience (composite measure)	no	distress (POMS)	effect	effect not in hypothesized direction	no effect
Good & Willoughby, 2014	adolescents; mean age 16 years; Canada	803	1 year	public religious activities, composite measure	yes	well-being (composite measure)	no effect		

(Table A.1 cont.)

Hebert et al., 2009	breast cancer patients; mean age 51 years; USA	284	T1: start of treatment T2: 8-12 months later	religiousness (composite measure), positive religious coping	yes	well-being (SF-36), depression (CES-D), life satisfaction (SWLS)	no effect		
Helms et al., 2014	adolescents; mean age 17 years; USA	265	1 year	church attendance, intrinsic religiosity	yes	depression (MFQ)	no effect		
Hettler & Cohen, 1998	protestant churchgoers: (A) conservative and (B) liberal; mean age 48 years; USA	A. 73 B. 51	8 months	intrinsic religiosity	yes	depression (CES-D)	no effect		
King et al., 2007	elderly receiving primary care; ≥ 65 years of age; USA	402	1 year	church attendance, private religious activities, intrinsic religiosity	yes	depression (HAMD)	effect of private religious activities (linear effect), but more depression	effect not linear	no effect

(Table A.1 cont.)

							among extremely high or low religious activities (quadratic effect)		
Koenig et al., 1992	medically ill hospitalized older male patients with depression; > 65 years (mean age 70 years); USA	202	mean interval 6 months	positive religious coping	no	depression (GDS)	effect		
Koenig et al., 1998 (other study group than Koenig et al., 1992)	medically ill, hospitalized people with depression; > 60 years; USA	87	47 weeks	intrinsic religiosity, church attendance, private religious activities	no	time to remission of depression	effect of intrinsic religiosity	1/3 tests significant	limited effect

(Table A.1 cont.)

Koenig, 2007	depressed medical in-patients with heart failure and/or CPD; mean age 68 years; USA	865	3.5 month	public, private religious activities, intrinsic religiosity, religiousness (composite measure)	yes	time to remission of depression	effect of public religious activities and religiousness	2/4 tests significant; correction for multiple testing applied	effect
Krause, 2007	population sample of elderly people; ≥ 65 years (mean age 75 years); USA	1092	2 - 3 years	meaning in life	yes	depression (shortened CES-D)	effect		
Law et al., 2009	population sample of elderly people; ≥ 70 years; mean age 76 years; Australia	627	T2: 2 years T3: 7 years	church attendance	yes	depression (CES-D)	effect of attending compared to not attending		

(Table A.1 cont.)

Leurent et al., 2013	adult general practice attendees; mean age NA; samples from different countries	A. 8318 B. 6094	1 year	A. life view religious, spiritual or neither B. strength of religious/ spiritual belief	yes	diagnosis of major depression (CIDI)	A. effect of spiritual life view compared to neither, but only in UK; B. effect of strength of religious or spiritual belief	effects not in hypothesized direction	no effect
Levin et al., 1996	population samples of Mexican Americans; median age (A) 27, (B) 50, (C) 73 years	A. 249 B. 260 C. 108	11 years	church attendance	Yes	depression (CES-D), positive affect, life satisfaction	effect on positive affect and depression among A.	2/9 tests significant; effect on positive affect not in hypothesized direction	no effect
Levin & Taylor, 1998	population sample of adult African Americans; mean age 53 years	582	12 – 13 years	Church attendance, public religious activity (church membership, church activity), private religious	yes	distress (MHI), happiness, life satisfaction	no effect		

(Table A.1 cont.)

				activities (reading religious books, listening to religious TV/radio), prayer, asking for prayer, subjective religiosity					
Marques et al., 2013	students; mean age 16 years; Portugal	A. 212 B. 183	A. 6 months B. 12 months	church attendance, finding religion important	no	life satisfaction	late effect of finding religion important	1/4 effects significant	no effect
Maton et al., 1989 study 2	Students; mean age NA; USA	68	5 months	spiritual support (subjective religiosity), church attendance	yes	depression (BSI)	no effect		
McIntosh et al., 2011	adult population sample, recruited after 9/11/2001; mean age 48 years; USA	890	3 years	church attendance, intrinsic religiosity	yes	new mental ailments, positive affect	effect of church attendance and intrinsic religiosity on positive affect; effect of church	3/4 tests significant	effect

(Table A.1 cont.)

							attendance on mental ailments		
Moskowitz et al., 2003	gay and bisexual men who lost their partner from AIDS; mean age 39 years; USA	86	18 - 24 months	religiosity (composite measure)	yes	depression (CES-D), well-being (PSOM).	no effect		
Musick et al. 1998	cancer patients; mean age 72 years; USA	251	3 years	church attendance, private religious activities (incl. using religious media)	yes	depressed, positive affect (CES-D)	effect of church attendance on positive affect, but only among black people	1/12 tests significant	no effect
Pargament et al., 2004	medically ill people; ≥ 55 years; USA	268	T1: in hospital T2: about 21 months later	positive religious coping	yes	depression (self-developed scale), quality of life	effect of demonic reappraisal of quality of life; effect of religious purification, religious	there was no reason to perform the tests on individual coping scales, as the authors indicated that additional analyses would only	no effect

(Table A.1 cont.)

							conversion and interpersonal religious discontent on depression	be conducted if the sum of the positive or negative religious coping scales emerged as an overall predictor, which was apparently not the case.	
Park et al., 2014	patients with chronic heart failure; mean age 67 years; USA	111	3 months	religious social support, public religious activities, positive religious coping, religious identity	yes	depression (CES-D), life satisfaction (SWLS)	effect of religious social support on life satisfaction	1/8 tests significant	no effect
Perez et al., 2009	students; 11-15 years; USA	1096	1 year	religiousness (composite measure)	yes	depressive disorder (CDI-interview)	indirect effect via self-efficacy and coping for girls, but not for boys	there was no reason to perform the separate tests for girls and boys, given the equivalence test. Moreover, their	no effect

(Table A.1 cont.)

								finding only proves that boys and girls differ in the relationship between coping and depression	
Pössel et al., 2011	students; mean age 15 years; USA	273	4 months	intrinsic religiosity	no	depression (CDI)	effect		
Rasic et al., 2011	adult population sample; ≥ 30 years; Canada	1091	8 – 12 years	religious attendance, seeking spiritual support	yes	major depression, anxiety disorder	no effect		
Rasic et al., 2013	adolescents; mean age 16 years; Canada	976	2 years	church attendance, importance of religion	yes	serious depression (CES-D)	effect of frequent attendance, but only among non-depressed girls and among depressed boys	2/8 tests significant	no effect

(Table A.1 cont.)

Reynolds et al., 2014	adolescents with cystic fibrosis or diabetes; mean age 15 years; USA	87	2 years	positive religious coping	yes	depression (BASC-2)	effect		
Ronneberg et al., 2014	(A) depressed and (B) non-depressed older adults; mean age 68 years; USA	A. 1992 B. 5740	2 years	church attendance, frequency of prayer, importance of religion, intrinsic religiosity	yes	depressive disorder (CES-D-8)	effect of private prayer among A.; effect of high and low attendance compared to moderate attendance among B.	3/12 tests significant; effect of attendance among B not in hypothesized direction	no effect
Schnittker, 2001	population sample; mean age NA; USA	2836	3 years	religious salience, church attendance, spiritual help-seeking	yes	depression (CES-D)	effect of religious salience (linear effect), but more depression with extremely high or low	effect of religious salience not linear; effect of spiritual help-seeking not in hypothesized direction	no effect

(Table A.1 cont.)

							salience (quadratic effect); effect of spiritual help-seeking
Sherman et al., 2009	myeloma patients undergoing bone marrow transplantation; mean age 56 years; USA	94	T1: before stem cell transplan-tation T2: on average 3 months later	religiousness, positive religious coping	no	anxiety, depression (BSI), emotional well-being (FACT-BMT)	no effect
Smith et al., 2000	church members who had been exposed to massive flooding; mean age NA; USA	131	T1: 6 weeks after the flood T2: 6 months after the flood	religiousness (composite measure), positive religious coping	yes	distress (GHQ)	no effect

(Table A.1 cont.)

Sun et al., 2012	population sample of elderly people; mean age 75 years; USA	1000	4 years	church attendance, private religious activities, intrinsic religiousness	yes	trajectories of depression over 5 time points	linear effect of high intrinsic religiousness; quadratic effect of moderate and low intrinsic religiousness	effect not linear	no effect
Tix & Frazier, 1998	(A) kidney transplant patients; mean age 42 years; (B) their significant others; mean age 46 years; USA	A. 174 B. 123	T1: 3 months after surgery T2: 12 months after surgery	positive religious coping	yes	distress (BSI), life satisfaction (SLS)	no overall effect; effect on life satisfaction among Protestant patients; effect on distress among Catholic significant others	there was no reason to perform the separate tests, as the interaction term of religious coping and religious affiliation was not significant; effect on distress not in hypothesized direction	no effect

(Table A.1 cont.)

Toussaint et al., 2012	adult population sample; mean age 46 years; USA	966	6 months	religiousness (composite measure)	yes	major depression (CIDI)	indirect effect of religiousness through forgiveness of others	effect
Trevino et al., 2010	patients with HIV/AIDS; mean age 43 years; USA	329	12 - 18 months	positive religious coping	yes	depression (CES-D 10), quality of life (HAT-QoL)	no effect	
Williams et al., 1991	population sample; mean age 45 years; USA	720	2 years	church attendance	yes	distress	no effect	
Wink et al., 2005	population sample of elderly people; age 65-70 years; USA	184	T1: 40-50 T2: 50-65 T3: 65-70 years of age	religious and spiritual salience (composite measures)	no	depression (CES-D)	no effect	

[a] Studies are only evaluated with respect to the eight R/S predictors, which are mentioned in the text

[b] At least control for one socio-demographic variables (age, gender, or income) and in studies with elderly or people with physical health problems one physical health variable

Table A.2 Summary of studies on the moderation effect of spirituality on the relationship between stressors and mental health

Author(s)	Sample characteristics	N	Interaction terms	Sufficient control [a]	Outcome variables	Design	Findings	Comment	Decision
Ai et al., 1998	cardiac surgery patients, one year after surgery; age 40-80 years; USA	151	using prayer for help x fatigue, shortness of breath, angina	no	distress	cross-sectional	no effect		
Bierman, 2006	population sample of (A) white and (B) black adults; mean age (A) 45 years, (B) 44 years; USA	A. 2581 B. 201	church attendance, religious comfort seeking x discrimination	yes	negative, positive affect	cross-sectional	effect of church attendance on negative affect among black adults	restriction of effect to black adults is understandable, because high level of discrimination; 1/4 effects significant	no effect
Braam et al., 1997	population sample; 55-89 years; The Netherlands	A. 129 B. 48	religious salience x chronic diseases, pain, functional limitations	no	depression A. incidence B. chronicity (CES-D≥16)	longitudinal; 1 year	effect on chronicity	3/6 tests significant; baseline depression corrected through differentiation between incidence and chronicity	limited effect

(Table A.2 continued)

Bradshaw & Ellison, 2010; same databank as Ellison et al. (2008), Ellison & Flannely (2009); wider sample, one wave instead of two	population sample of adults; mean age 45 years; USA	1140	church attendance, prayer, meditation, belief in afterlife x objective, subjective financial hardship	yes	distress	cross-sectional	effect of church attendance, meditation, and belief in afterlife by objective financial hardship; effect of church attendance and belief in afterlife by subjective hardship	5/8 tests significant	effect
Chaudoir et al., 2012	adults with HIV/AIDS; mean age 43 years; USA	465	peace/meaning x perceived HIV-stigma	yes	depression (CES-D 10)	cross-sectional	effect		

(Table A.2 cont.)

Davis & Epkins, 2009	(A) students, (B) their mothers; mean age (A) 11-12 years, (B) 41 years; USA	170	private religious practices x family conflicts	no	depression (CDI), anxiety (RCMAS)	cross-sectional	effect among both A. and B.		
Dezutter et al., 2010	patients with chronic pain; mean age 53 years; Belgium	207	importance of R/S x pain severity	yes	life satisfaction (SWLS)	cross-sectional	effect		
Ellison, 1991	population sample of adults; mean age NA; USA	909	composite measure, existential certainty x traumatic events	yes	happiness, life satisfaction	cross-sectional	effect of existential certainty	2/4 tests significant; explanation for limited effect provided	effect
Ellison et al., 2008; same as Ellison & Flannely (2009)	population sample of adult African Americans; mean age 50 years	645	church attendance, religious guidance, support from church members x racial discrimination	yes	distress (RAND MHI)	longitudinal; 3 years	effect of religious guidance and attending church more than once a week compared to few times a month	2/3 tests significant	effect

(Table A.2 cont.)

Ellison & Flannelly, 2009	population sample of adult African Americans; mean age 50 years	607	religious guidance x stressful life events	yes	major depression (NIHM diagnostic interview)	longitudinal; 3 years	no effect		
Helms et al., 2014	adolescents; mean age 17 years; USA	265	church attendance, intrinsic religiosity x physical, relational victimization	yes	depression (MFQ)	longitudinal; 1 year	effect of intrinsic religiosity by relational victimization	1/4 tests significant	no effect
Hettler & Cohen, 1998	Protestant churchgoers: (A) conservative and (B) liberal; mean age 48 years; USA	A. 73 B. 51	intrinsic religiousness, importance of religion, church attendance, prayer frequency x life events	yes	depression (CES-D)	longitudinal; 8 months	effect, but only among liberal protestants	4/8 tests significant; explanation for limited effect provided	effect

(Table A.2 cont.)

Idler & Kasl, 1997	population sample; mean age 75 years; USA	2812	religious attendance, subjective religiousness x disability	yes	depression, positive, negative affect	cross-sectional	effect of religious attendance on positive affect	1/6 test significant	no effect
Kim & Seidlitz, 2002	students; median age 20 years; Korea	113	spirituality x daily hassles, spirituality x daily hassles x religious affiliation	no	positive, negative affect (PANAS)	cross-sectional	effect on negative affect, which was stronger among students with a religious affiliation		effect
Krause, 2007	population sample of elderly people; ≥ 65 years (mean age 75 years); USA	1092	meaning in life x stressful life events	yes	depression (shortened CES-D)	cross-sectional, longitudinal; 2-3 years	cross-sectional effect; no longitudinal effect	longitudinal effect decisive	no effect
Maton et al., 1989 (study 1)	bereaved parents; mean age 46 years; USA	81	spiritual support x child died within last two years vs longer ago	yes	depression (HSCL)	cross-sectional	no effect		

(Table A.2 cont.)

Maton et al., 1989 (study 2)	students; mean age NA; USA	68	spiritual support x number of life events	yes	depression (BSI)	longitudinal; 5 months	no effect		
Mirola, 1999	population sample of adults; mean age NA; USA	700	church attendance, taking church responsibilities, religious involvement, praying to cope x chronic role strains	yes	depression (BSI)	cross-sectional	effect of using prayer to cope, but only among women	1/8 tests significant	no effect
Pollner, 1989	population sample of adults; mean age NA; USA	2927	composite measure x traumatic life events	yes	happiness, life satisfaction	cross-sectional	no effect		
Pössel et al., 2011	students; mean age 15 years; USA	273	intrinsic religiousness x life events	no	depression (CDI)	longitudinal; 4 months	no effect		

(Table A.2 cont.)

Schnittker, 2001	population sample; mean age NA; USA	2836	importance of religion, church attendance, spiritual help-seeking x life events (one, two or more)	yes	depression (CES-D)	longitudinal; 3 years	effect of importance of religion and spiritual help-seeking by having experienced two or more life events	2/6 tests significant	limited effect
Siegel & Kuykendall, 1990	population sample of elderly people; ≥ 65 years; USA	825	church membership x death of family member (not spouse)	yes	depression (CES-D)	cross-sectional	effect, especially among widowed men		
Strawbridge et al., 1998	population sample of elderly people; ≥50 years; USA	2537	church attendance, importance of religion x non-family stressors (financial problems, neighborhood problems, poor health, chronic	yes	depression (two items from DSM-III-R scale)	cross-sectional	Non-family stressors: effect of church attendance by financial problems and total number of problems; effect of importance of religion financial	9/18 tests significant; results for family stressors not in the hypothesized direction	no effect

(Table A.2 cont.)

			illness, disability), family stressors (abuse, marital problems, caregiving, child problems)				problems, poor health, and total number of stressors Family stressors: effect of church attendance by child problems; effect of importance of religion by abuse, caregiving and total number of stressors		
Williams et al., 1991	population sample; mean age 45 years; USA	720	church attendance, religious affiliation (y/n) x stressful life events, health problems	yes	distress	longitudinal; 2 years	effect of church attendance	2/4 tests significant; explanation for limited effect provided	effect

(Table A.2 cont.)

Wink et al., 2005	population sample of elderly people; age 65-75 years; USA	184	religiousness, spirituality (composite measures) x physical health	no	depression (CES-D)	cross-sectional at T3, longitudinal; T1: 40-50 T2: 50-65 T3: 65-70 years of age	cross-sectional effect; longitudinal effect of T1 religiousness	3/6 tests significant; explanation for limited effect provided	effect

[a] At least control for one socio-demographic variables (age, gender, or income) and in studies with elderly or people with physical health problems one physical health variable

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Samenvatting (Summary in Dutch)

Achtergrond

De diagnose en behandeling van kanker zijn voor veel mensen een stressvolle periode, omdat er veel veranderingen plaatsvinden. De diagnose van kanker kan mensen doen beseffen dat het leven eindig is en gezondheid niet vanzelfsprekend, wat allerlei existentiële vragen kan oproepen over rechtvaardigheid en over wat écht van waarde is. Daarnaast is de persoon niet meer een gezonde persoon, maar een patiënt, en treden er door de behandeling allerlei lichamelijke symptomen op zoals vermoeidheid, misselijkheid en pijn. Het werkende leven en gezinsleven worden (voor lange of korte tijd) doorbroken door regelmatige bezoeken aan het ziekenhuis. Zelfs als de ziekte genezen kan worden, kan de persoon achterblijven met de onzekerheid over eventuele terugkeer van de kanker. Al deze veranderingen en onzekerheden kunnen de relaties, identiteit en betekenis van het leven van de persoon onder druk zetten. Uit verscheidene onderzoeken blijkt dan ook dat 12 tot 30% van de mensen met kanker langdurige psychische problemen ervaart (al dan niet van klinische aard), soms wel tot zes jaar na de operatie.

Een aantal psychologische factoren lijkt mensen te beschermen tegen langdurige psychische klachten: Een positieve levenshouding (bijvoorbeeld, zelfwaardering, optimisme, weinig pessimisme, 'mastery', weinig neuroticisme, en/of een gevoel van controle), de afwezigheid van eerdere psychische problemen en sociale steun. Ook spiritualiteit kan een bron van veerkracht zijn voor mensen met kanker. Inderdaad is er in diverse onderzoeken gevonden dat mensen met kanker hun spiritualiteit beschrijven als een bron van kracht, steun en zingeving tijdens het ziekteproces.

Spiritualiteit kan om verschillende redenen belangrijk zijn tijdens de psychologische aanpassing aan kanker. Ten eerste kan spiritualiteit een bron zijn van sociale steun. Deze steun komt niet alleen van andere mensen, maar ook van God, de natuur, of een andere kracht of macht die de persoon ervaart. Ten tweede zijn mensen die zich bezighouden met spiritualiteit over het algemeen optimistischer dan mensen die minder bezig zijn met spiritualiteit. Ten derde lijkt het erop dat mensen die zich bezig houden met spiritualiteit meer geneigd zijn om op een probleemgerichte manier met moeilijke situaties om te gaan (zogenaamde approach-oriented coping), in plaats van ze te vermijden, wat behulpzaam is bij de aanpassing aan negatieve situaties. Vooral het herwaarderen van een situatie lijkt typerend te zijn voor mensen die zich actief bezighouden met spiritualiteit. De herwaardering van een situatie vanuit spiritueel perspectief is echter niet altijd positief. Vooral wanneer de gebeurtenis niet congruent is met spirituele overtuigingen, ervaringen of waarden, kan het zijn dat een persoon, bijvoorbeeld, teleurgesteld raakt in zijn/haar spiritualiteit, zich gestraft voelt, of zich afkeert van zijn/haar spiritualiteit. Deze situatie kan nog meer negatieve emoties tot gevolg hebben. Diverse onderzoeken wijzen er echter op, dat wanneer de spirituele levenshouding congruent is met de situatie en wordt ervaren als consistent en geloofwaardig, het de persoon juist kan helpen om zin te vinden in de negatieve gebeurtenis en hier op een positieve manier mee om te gaan.

Spiritualiteit

Er wordt veel onderzoek gedaan naar of en hoe spiritualiteit bijdraagt aan de psychologische aanpassing aan kanker. Helaas weten we nog erg weinig over de relatie tussen niet-religieuze spiritualiteit en de aanpassing aan kanker, zoals blijkt uit een literatuuronderzoek van 40 studies op dit gebied, die waren gepubliceerd tot en met het jaar 2009 (**hoofdstuk 2**). Ten eerste hadden de meeste studies een cross-sectionele onderzoeksmethode gebruikt, wat betekent dat er geen conclusies konden worden getrokken over de aard van de relatie tussen spiritualiteit en aanpassing. Ten tweede hadden de meeste studies definities en meetinstrumenten van spiritualiteit gebruikt die al verwezen naar welbevinden, wat betekent dat conclusies uit deze studies gebaseerd waren op een cirkelredenering. Vooral dit laatste is een groot probleem voor onze kennis over de relatie tussen spiritualiteit en de psychologische aanpassing aan kanker.

Maar wat is (niet-religieuze) spiritualiteit eigenlijk? Er bestaan veel uiteenlopende definities van spiritualiteit, zowel onder de algemene populatie als onder wetenschappers. Twee thema's komen echter steeds weer terug: Verbondenheid en betekeniservaring. Voor ons onderzoek zijn ik en mijn collega's daarom uit gegaan van de definitie van spiritualiteit als 'iemands streven naar en ervaring van verbondenheid met de essentie van het leven'. Deze essentie van het leven kan gevonden worden in de persoon zelf, in de omgeving, in de natuur, of in een grotere kracht of macht. Spiritualiteit uit zich als een ervaring van betekenis en doel in het leven, verbondenheid met de natuur, en/of transcendente ervaringen; een houding van vertrouwen in zichzelf, aanvaarding van zowel het positieve als het negatieve in het leven, en/of compassie en zorg voor anderen; en betrokkenheid in spirituele activiteiten. Natuurlijk kan dit alles zich afspelen binnen een religie, maar dat hoeft niet.

Het lastige van een dergelijke definitie van spiritualiteit is dat het ontzettend breed is en het niet erg duidelijk is waar spiritualiteit eindigt en andere positieve psychologische concepten beginnen. Vooral zinervaring, vertrouwen en aanvaarding zouden wel eens gevolgen kunnen zijn van spiritualiteit, in plaats van aspecten ervan. Om hier meer duidelijkheid over te krijgen hebben we onderzocht of het meetinstrument dat wij zelf gebruiken om de mate van spiritualiteit van mensen mee vast te stellen (de Spirituele Attitude en Interesse Lijst, of SAIL) overlap vertoont met ons meetinstrument voor welbevinden (**hoofdstuk 3**). Dit hebben we op drie manieren gedaan: (a) het toepassen van principale componentenanalyse op itemniveau, (b) het vergelijken van het beloop van spiritualiteit, met het beloop van welbevinden, gedurende het eerste jaar na de diagnose van kanker, en (c) het vergelijken van de samenhang van spiritualiteit met lichamelijke symptomen en negatieve levensgebeurtenissen, ten opzichte van de samenhang van welbevinden met lichamelijke symptomen en negatieve levensgebeurtenissen. We concludeerden dat vertrouwen inderdaad meer lijkt op welbevinden dan op spiritualiteit, maar dat de andere aspecten van spiritualiteit niet lijken op welbevinden. De SAIL, minus de sub-schaal Vertrouwen, kan daarom goed gebruikt worden in onderzoek naar de rol van spiritualiteit in de aanpassing aan kanker.

Natuurlijk is de SAIL niet het enige meetinstrument van spiritualiteit dat de afgelopen jaren is ontwikkeld, en het is voor onderzoekers vaak moeilijk om een keuze te maken tussen al deze verschillende instrumenten. Daarom hebben we ook onderzocht welke andere meetinstrumenten weinig overlap vertonen met welbevinden (**hoofdstuk 4**). Door van negen spiritualiteitsvragenlijsten het percentage items vast te stellen dat verwijst naar welbevinden of een relatie tussen spiritualiteit en welbevinden (bijvoorbeeld, 'mijn religie geeft mij steun'), kwamen we tot de conclusie dat de Jarel spiritual well-being scale en de Spiritual Well-Being Questionnaire (SWBQ, ook wel bekend als de SHALOM) weinig overlap vertonen met maten voor welbevinden. De psychometrische eigenschappen van de Jarel zijn echter onvoldoende vastgesteld, dus we raadden het gebruik hiervan af. De SWBQ bleek daarmee, naast de SAIL, het meest bruikbaar voor onderzoek naar de rol van spiritualiteit in de aanpassing aan kanker onder een brede populatie.

Spiritualiteit en de psychologische aanpassing aan kanker

In ons literatuuronderzoek van studies tot 2009 (**hoofdstuk 2**) hadden we vastgesteld, dat de meeste onderzoeken een cross-sectionele onderzoeksmethode hadden gebruikt, waardoor er weinig bekend was over de richting van de relatie tussen spiritualiteit en de psychologische aanpassing aan kanker. Om hier meer inzicht in te krijgen ondernamen we een tweede systematisch literatuuronderzoek (**hoofdstuk 5**). Hierin evalueerden we 73 studies, gepubliceerd tot en met 2014, die de directe lange-termijn relatie van zowel religieuze, als niet-religieuze spiritualiteit met welbevinden hadden onderzocht, of die hadden onderzocht of spiritualiteit een modererende rol speelde in de relatie tussen verscheidene stressoren en welbevinden. Het bleek dat mensen die sturing in hun leven ervaren van hun religie en/of die religie belangrijk vinden in hun leven, op de langere termijn meer welbevinden rapporteren en minder negatieve effecten ervaren van stressvolle omstandighed. Dit beschermende effect van spiritualiteit kwam vooral naar voren in studies onder mensen met lichamelijke klachten. Opvallend was echter, dat de overgrote meerderheid van de studies alleen beperkte aspecten van religieuze spiritualiteit had onderzocht. Bovendien waren maar 3 van de 73 studies onder mensen met kanker uitgevoerd.

Om dit gebrek aan kennis op te vullen hebben wij twee onderzoeken uitgevoerd naar het effect van diverse aspecten van niet-religieuze spiritualiteit op de aanpassing aan kanker-gerelateerde stressoren (**hoofdstuk 6**). In de eerste, cross-sectionele studie onderzochten we onder 216 mensen met kanker, die hiervoor met curatieve of palliatieve intentie werden behandeld, of spiritualiteit de negatieve relatie van pijn en vermoeidheid met welbevinden en distress (een combinatie van depressie en angst) verzwakte. We vonden geen aanwijzingen voor een dergelijk modererend effect van spiritualiteit, maar diverse aspecten vertoonden wel een directe relatie met hoger welbevinden of lagere distress. Een tekortkoming van deze studie is echter, dat we alleen het statische niveau van pijn en vermoeidheid hebben onderzocht, terwijl juist een verandering in deze symptomen aanpassing vraagt en een negatieve invloed kan hebben op welbevinden/distress. Daarom

hebben we in de tweede, longitudinale studie onderzocht of spiritualiteit het negatieve effect van veranderingen in pijn, vermoeidheid en de ervaring van levensbedreiging door de kanker op welbevinden en distress vermindert. Dit deden we onder 383 mensen met kanker, die hiervoor met curatieve intentie werden behandeld, en gedurende twee perioden van zes maanden na het begin van de behandeling. Betreffende de eerste zes maanden na het begin van de behandeling, vonden we inderdaad dat de ervaring van betekenis en doel in het leven de negatieve invloed van toegenomen vermoeidheid op distress lijkt te verminderen. Gedurende de zes maanden daarna, waren het een houding van aanvaarding en spirituele activiteiten die het negatieve effect van vermoeidheid leken te verminderen. Daarnaast vonden we aanwijzingen dat aanvaarding ook het negatieve effect verminderde van een toename in ervaren levensbedreiging op distress. Daarentegen leek de houding van zorg voor anderen juist het negatieve effect van een toename in levensbedreiging te versterken. Net als in ons literatuuroverzicht vonden we dus meer aanwijzingen voor een stress-verminderend effect van spiritualiteit, dan voor een direct effect op de aanpassing aan kanker.

Om toch wat meer te weten te komen over het directe effect van spiritualiteit, onderzochten we onder de 383 eerder genoemde mensen met kanker of hun mate van aanpassing verschilde wanneer zij zich religieus, spiritueel, allebei, of geen van beiden vonden (**hoofdstuk 7**), in plaats van het effect van de diverse losse aspecten van niet-religieuze spiritualiteit te onderzoeken. Deze vier categorieën representeren verschillende soorten spiritualiteit, die ieder een andere invloed kunnen hebben op de aanpassing aan kanker. We toetsten of de vier groepen verschilden in het beloop van welbevinden en distress gedurende twee perioden van zes maanden na het begin van de behandeling van kanker, en of eventuele groepsverschillen in aanpassing verklaard zouden kunnen worden door verschillen in ervaren sociale steun, tevredenheid met de partnerrelatie, optimisme, of copingstijl. We vonden echter geen groepsverschillen in welbevinden of distress, ook al gaven de mensen die zich alleen spiritueel vonden of die zich zowel religieus als spiritueel vonden wel vaker aan de probleemgerichte copingstijlen van actieve coping en sociale steun zoeken te hanteren, dan de mensen die zich als alleen religieus of als niet religieus noch spiritueel beschouwden.

Omdat we vrij weinig aanwijzingen hadden gevonden voor een langere-termijn relatie tussen spiritualiteit en de aanpassing aan kanker, terwijl er wel een cross-sectionele relatie lijkt te bestaan tussen die twee, voerden we een kwalitatief onderzoek uit onder tien zeer spirituele mensen met kanker uit de voorgaande studie (**hoofdstuk 8**). Deze deelnemers gaven aan dat vooral de overtuiging dat de ervaring van kanker onderdeel was van een grotere taak van de persoon, de ervaring van een persoonlijk betrokken en helpende God, en de handeling van gebed hen hadden geholpen bij het omgaan met de diagnose en behandeling van kanker. Deze aspecten van spiritualiteit leken te helpen om een positieve betekenis te geven aan de gebeurtenis en om direct emoties te reguleren.

Toekomstig onderzoek

Er zijn meerdere redenen aan te wijzen waarom we in de bovenstaande onderzoeken beperkte aanwijzingen vonden voor een effect van spiritualiteit op de psychologische aanpassing aan kanker. Het zou bijvoorbeeld kunnen, dat we de belangrijke gebeurtenissen in het aanpassingsproces aan kanker hebben gemist. In onze longitudinale studie lagen de meetmomenten wel zes maanden uit elkaar, terwijl eerder onderzoek erop wijst dat de meest stressvolle gebeurtenissen tijdens het behandelingstraject van kanker veel dichter op elkaar liggen in de tijd. Toekomstig onderzoek zou dus meer meetmomenten moeten gebruiken, die samenvallen met klinisch relevante gebeurtenissen.

Het kan ook zijn dat we de verkeerde aspecten van spiritualiteit en welbevinden hebben gemeten. Uit het kwalitatieve onderzoek (**hoofdstuk 8**) bleek dat vooral de overtuiging dat er een grotere betekenis was achter het krijgen van kanker, de ervaring van steun van God en gebed als behulpzaam werden ervaren. In het literatuuronderzoek over het directe lange termijn effect en het modererende effect van spiritualiteit (**hoofdstuk 5**) vonden we vergelijkbare resultaten. We hebben deze aspecten niet expliciet gemeten in onze kwantitatieve onderzoeken. Daar komt nog bij dat het primaire doel van spiritualiteit niet is om meer welbevinden te ervaren, maar om verbonden te zijn met het diepere, bredere, of hogere, en om hierin de betekenis en doel van het leven te vinden. In de context van kanker zijn uitkomstmaten zoals een gevoel van controle, situationele betekenis, 'sense of coherence', en spirituele groei wellicht relevanter dan stemming-gerelateerde maten zoals welbevinden en distress. Toekomstig onderzoek zou dus maten voor spiritualiteit en uitkomstmaten moeten gebruiken die dichter liggen bij de essentie van spiritualiteit: Betekeniservaring en verbondenheid. Daarbij is het van belang meer aandacht te hebben voor de verschillende manieren waarop mensen spiritueel kunnen zijn. Spiritualiteit is in hoge mate een persoonlijk proces dat voor iedereen een ander gevolg kan hebben voor de psychologische aanpassing aan kanker. Het is daarom nodig om meer vergelijkend, multidisciplinair, gemengde-methoden onderzoek te doen, dat gestructureerd wordt met behulp van een sterk theoretisch kader.

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About the author

Anja Visser was born in Heerenveen on August 27, 1984. In 2005 she obtained her bachelor degree in psychology at Tilburg University, with a major in Clinical Health Psychology and a minor in Cognitive Neuroscience. She went on to obtain her master degree in 2007 in the Researchmaster program Social and Behavioral Sciences at Tilburg University, specializing in Medical Psychology. For her master thesis she investigated the association between experiencing a relationship with God and mental well-being among people with non-small cell lung cancer. The study was supervised by dr. Yori Gidron.

In 2008 Anja Visser was employed as a PhD student at the Helen Dowling Institute. Her PhD research focused on the relationship between spirituality and well-being among cancer patients treated with curative intent. In 2010 the Helen Dowling Institute obtained a research grant from the Dutch Cancer Society for the project Spiritual Nursing in Curative Cancer Care, which was co-authored by Anja. She currently serves on the advisory committee of this project. In 2012-2013 she conducted a study at the Helen Dowling Institute on the practice of oncology nurses at the Maasstad hospital, Rotterdam. This study was commissioned by the Stichting Geestelijke Verzorging Rijnmond and the Maasstad hospital.

Since 2013 Anja works as assistant professor of psychology at University College Roosevelt, Middelburg. In 2013 she also acted as a freelance statistician for the determination of the psychometric characteristics of a Dutch translation of the Primary Care Resources and Supports for Chronic Disease Self-Management, commissioned by Boehringer Ingelheim b.v.. Anja has been a member of the editorial board of the Dutch Journal of Behavioral Medicine since 2010 and became the senior editor of this journal in 2015.

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